

**Unravelling the duality of Caregivinghood**  
**How informal caregivers describe their situations when**  
**salutogenically approached**

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UNIVERSITY OF  
GOTHENBURG

Cover-illustration; explanations in Swedish and English

Ibland möter du som kommunköterska äldre personer vars kunskap och livserfarenhet leder till djupa samtal som sätter outplånliga spår i ens hjärta. Lappen på omslaget är skriven av en äldre herre en oändlig vinternatt 1997 under ett av de långa nattliga samtal vi hade när jag besökte honom som nattsköterska. Vi talade om livet och hans älskade livskamrat som nyligen avlidit under en av de många resor vi tillsammans skickade iväg henne på till lasarettet, men framför allt talade vi om livsglädje. Äldre personers livsglädje var vid den tiden fokus i den kandidatuppsats jag höll på att författa. Denne man hade så oändligt mycket klokskap att förmedla och återkom ofta till kärnan i den levnadsdevis som finns på omslaget (hans tolkade översättning); Även om man inte klarar av allting när kroppen inte längre orkar, är det synnerligen aktningsvärt att man försöker, så som han gjort under ett långt liv för att underlätta för sin älskade livskamrat. Jag bad honom skriva ner levnadsdevisen för att kunna ha den på omslaget till min avhandling om jag någonsin skrev någon, fast han hävdade när jag skrev den, vilket jag nu gjort! Denne kloke akademiker har sedan länge gått ur tiden, men hans handskrivna lapp har jag kvar ovanför mitt skrivbord. Jag är övertygad om att han följt mina ansträngningar och nu ler och känner stolthet över att hans bidrag till detta akademiska verks tillkomst var synnerligen aktningsvärt och i allra högsta grad ovärderligt. Tack för att du, med all din visdom, var med i mina tankar under den här resan!

At times, you meet individuals as a homecare nurse who leave everlasting footprints in your heart. The note on the cover was written by a true gentleman one endless winter night in 1997 during one of our many conversations when I visited him as a night-nurse. We talked about life and his beloved life-partner, who had recently passed away during one of the many journeys to the hospital to which we regularly sent her. However, most of all we talked about 'Joy-in-living' amongst older adults, which was the topic for a bachelor's degree paper I was working on at that time. This senior academic had infinite amounts of wisdom to share and often returned to the core of an adage that had guided his life, the one displayed on the cover of this thesis; Even if you cannot manage everything when your body becomes increasingly fragile, it is highly estimable that you try. This was what he had tried to do during a long life with his chronically incapacitated, beloved partner. He wrote the adage down on a piece of paper he found on his kitchen-table so that I could put it on the cover of my thesis, if I ever wrote one.... but he told me when I wrote it, which I finally have! This wise old man has long since passed away, but I am convinced that he is proudly watching me and can see how highly estimable his contributions during those endless nights have been for the creation of this thesis. I sincerely thank you for being with me all this time, wherever you are!

Unravelling the duality of Caregivinghood -  
How informal caregivers describe their situations when salutogenically approached

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*To all of you who have supported me in every possible way during this journey!*



## PERSONAL PREFACE AND PRECONCEPTION

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Ever since I was a little girl picking flowers to older neighbors, combing my grandmother's silvery hair into plaits with my fingers or when taking care of her during the last months of her life, I have been fascinated by the stories which older adults narrated from their long lives. This interest persisted, and my first part-time employment was as a home helper on week-ends in Gothenburg's oldest parts. I met people who had grown up living thirteen in one-room apartments, men who had escaped this crowdedness as mates on sailing-ships and women who had left the poverty on small farms to serve as maids in wealthy city homes. It did not matter that I, at seventeen, merely could boil potatoes as long as I wanted to listen to their life-stories. It was a salutogenic experience that permeated my future life and choice of career.

This professional career continued as a nurse's assistant, a homecare nurse, a midwife and a homecare nurse again. Except for a few years in midwifery, I have been providing homecare to older adults during decades, and still is. When returning from midwifery in 1993, the ÄDEL-reform (1) had changed the perspectives. From my point of view older adults were now 'adapted' to the organization of homecare, instead of vice-versa as it had been prior to the reform. I disagreed with this development and started studying for degrees in nursing science, whilst working nights and taking care of my children during daytime, to be able to argue for a change. The main research interest was always older adult's ability to manage, their resources and what was essential to make their lives as enjoyable as possible, regardless of whether they needed assistance or not. This focus evolved as research questions and a concept labelled 'Joy-in-living'; livsglädje in Swedish (2, 3). In 2000, I participated in the course; Salutogenesis – from theory to practice, was enlightened and provided with a theory that made sense out of what I had been doing in my professional life and searched for when studying. The 'Joy-in-living'-concept fell right into the realms of salutogenic theory, became coherent, manageable and added meaning during battles with a context that tended to focus on older adults' deficits, instead of on their resources. I had found a theory to support my professional actions and guide my thinking during research.

This research evolved when I was accepted as a doctoral student based on previous work regarding the 'Joy-in-living' concept. However, the focus was changed towards informal caregivers to older adults and how they perceived their situation. I have met many informal caregivers during my professional career, some had really burdensome situations, some less so. The fascinating reality was the discrepancy between some caregivers' subjective perceptions of their situation and my professionally assessed 'objective' opinion, until I knew them better. This discrepancy was intriguing, and I wanted to use my clinical experience to derive knowledge regarding why some caregivers found caregiving less of an ordeal than others who, objectively, seemed to have equally burdensome situations; What generated their Joy-in-living, which were their resources, or salutogenically speaking, their Specific and Generalized Resistance Resources (SRRs/GRRs)? Which hindrances did they experience for using them, that is, which were their Specific and Generalized Resistance Deficits (SRDs/GRDs)? If we knew, would it be possible to work out of a more resource oriented perspective and could knowledge regarding their SRRs/GRRs and SRDs/GRDs change the manner in which homecare and caregiver support is organized?

These thoughts have served as a compass during a long, frequently cumbersome, journey across an academic sea imbued by shoals, until now when I seem to have reached a new horizon; I hereby invite you all to embark on this journey!

Sincerely yours,  
Mia Wennerberg



## ABSTRACT

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Demographic changes and an emphasis on community care, increase the number of informal caregivers to older adults in most societies. Their willingness to provide care and that they are healthy enough to manage, is essential. To preserve and promote their health is subsequently a prioritized challenge for homecare professionals, a topic on political agendas and in research. How this may be achieved is vividly debated, and mainly focused on elimination of risks and negative aspects associated with caregiving. This situation is dual and encompasses positive and negative aspects. Caregivers' health may be promoted from both directions, but far less knowledge exists regarding positive aspects and resources to health, than regarding negative aspects deteriorating it. This is unfortunate since health promotion focusing such salutogenic resources is effective.

The overall aim of the study in this thesis was to derive congruent knowledge concerning what informal caregivers' Specific and Generalized Resistance Resources, SRRs/GRRs and Deficits, SRDs/GRDs may consist of, and to suggest how such knowledge may be used to promote their health. The design was theory-driven and mainly qualitative. Data was analyzed using inductive within-case and deductive across-case analysis focused on caregivers' tension management, and the design allowed a contextually grounded generalizable synthesis of findings (I).

Findings unravelled SRRs/GRRs and SRDs/GRDs originating from the caregiver (II, III), carerecipient (II, III), dyad (IV) and environment/context (V). These resources and deficits consisted of individualized, generalized, circumstantial or contextual characteristics described as empowering, enabling, facilitating (resources) or impeding, hampering, obstructing (deficits) caregivers' ability to acquire a 'fit' between usable resources and a desired outcome during tension management. In the synthesis, Being situated in the duality of Caregivinghood, Caregivinghood is viewed as a continuum similar to the salutogenic health ese/dis-ease continuum. The experience of having access to resources, or experiencing deficits, determines a person's movements between the continuum's two end-points. According to salutogenic theory, SRRs and SRDs thereby determine the strength of a person's SOC. A strong SOC is associated with positive health development, thereby knowledge regarding what these resources and deficits consist of is essential. Due to the nature of these concepts, health promotion should be individualized and generalized, focus on preservation of SRRs/GRRs, elimination of SRDs/GRDs and providence of GRRs when appropriate ones are lacking. This knowledge could add to the health policy documents needed at a generalized level, thereby this type of health promotion could be beneficial, not only for caregivers, but for most inhabitants where it is conducted. The study adds new knowledge to the salutogenic framework which has to be evaluated through theoretical discussions and research, since findings have the potential to explain how the SOC may be strengthened.

**Keywords:** Caregivinghood, Community care, Dyad, Environment/context, GRD-definition, Health promotion, Homecare, Informal caregiver and carerecipient, Policy, Specific and Generalized Resistance Resources and Deficits, Salutogenesis, Support, Theory-driven qualitative design

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## ORIGINAL PAPERS

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This thesis is based on the following papers, referred to in the text by their Roman numerals.

- I Wennerberg, M. M.T, Lundgren, S.M & Danielson, E. (2012). Using the salutogenic approach to unravel informal caregivers' resources to health: Theory and methodology.  
*Aging & Mental Health, 16:3, 391–402.*
- II Wennerberg, M.M.T, Eriksson, M, Danielson, E & Lundgren, S.M. (2016). Unravelling Swedish informal caregivers' Generalised Resistance Resources.  
*Scandinavian Journal of Caring Sciences, 30: 602-613.*
- III Wennerberg, M.M.T, Eriksson, M, Lundgren, S.M & Danielson, E. Unravelling Swedish informal caregivers' Generalised Resistance Deficits.  
*Scandinavian Journal of Caring Sciences, Epub ahead of print, April 20, 2017, doi:10.1111/scs.12446.*
- IV Wennerberg, M.M.T, Lundgren, S.M, Eriksson, M & Danielson, E. Me and You in Caregivinghood – Dyadic resistance resources and deficits out of a caregiver perspective.  
*Manuscript*
- V Eriksson, M, Wennerberg, M.M.T, Lundgren, S.M & Danielson, E. “Self-employed” during Caregivinghood: The contribution of Swedish Informal Caregivers' Environmental and Contextual Resistance Resources/Deficits for Health Promotion Initiatives.  
*Re-submitted*

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## ABBREVIATIONS AND CORE-CONCEPTS

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*Caregiving dyad* – The caregiver-carerecipient viewed as a unit.

*Caregivinghood* – A label used for the specific phase of life when someone is providing informal care (examples of other such phases; youth, parenthood, third age)

*Caregiver (informal), CG* – In this thesis a European definition was used; ‘a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework’ (4). Some references use ‘carer’.

*Care manager* – An official who has specific responsibilities within a municipality’s elder care organizations, such as assessment of support needs. For an overview of specific concepts in the Swedish welfare organization see Krevers et al.(5).

*Carerecipient, CR* – The person to whom informal or formal caregivers provide care or nursing. Some references use ‘care recipient’.

*Communal* – The concept is used as a synonym to ‘shared’ in association with the caregivers, not as a reference to characteristics in the ‘municipality’ in which caregiving takes place.

*Context/contextual* – Immaterial characteristics within the dyad, specific situations or the surrounding context wherein caregiving takes place.

*Environment/environmental* – Physical and material characteristics within the caregiving dyad’s immediate surroundings or environment wherein caregiving takes place.

*Empowerment* – A multifaceted concept which may encompass different aspects depending on the context in which it is used (6). This thesis adheres to the broad definition of empowerment as the process that helps people take control over aspects that affect their life, such as health-determinants (7, 8). This process may involve individuals, groups, professionals and organizations on local, national and international levels. Someone who is empowered is not powerless, but an individual capable to influence her/his context in a way that is beneficial for that individual without harming others or their mutual environment. (For empowerment and nursing, for example Gibson (9).

*Formal care and formal caregivers* – The organization and professional providers of care and nursing.

*Generalized Resistance Resources, GRRs* – Generalized, contextual, material and immaterial characteristics that enables an individual, or group, to effectively manage the tension aroused by something appraised as a challenge in a health promoting manner (10-12).

*Specific Resistance Resources, SRRs* – Individual, contextual, material and immaterial characteristics that enables an individual to effectively manage the tension aroused by something they have appraised as a challenge in a health promoting manner (10-12).

*Generalized Resistance Deficits, GRDs* – Generalized, contextual, material and immaterial characteristics that counteract the use of SRRs/GRRs, or indicates a lack of usable, appropriate ones when facing a challenge (10-12).

*Specific Resistance Deficits, SRDs* – Individual, contextual, material and immaterial characteristics that counteract the use of SRRs/GRRs, or indicates a lack of usable, appropriate ones when facing a challenge (10-12).

*Health* – In this thesis a salutogenic approach to the health concept described by Eriksson (13 p. 18) is used; *'The concept of health integrates physical, mental, social and spiritual health on individual, group or societal level. The concept thereby 'emphasises the importance of structured and empowering environments, where people are able to identify their internal and external resources, use and reuse them in order to realize aspirations, to satisfy needs, to perceive meaningfulness and to cope with changes in a health promoting manner'*. Health is viewed as a resource for life, not the main goal.

*Health promotion* – In this thesis the expanded definition based on the Ottawa Charter for health promotion (7), and a synthesis of salutogenic research between 1992-2003 by Eriksson is used; *'Health promotion is the process of enabling individuals, groups or societies to increase control over, and to improve their physical, mental, social and spiritual health. This could be reached by creating environments and societies characterized of clear structures and empowering environments where people see themselves as active participating subjects who are able to identify their internal and external resources, use and reuse them to realize aspirations, to satisfy needs, to perceive meaningfulness and to change or cope with the environment in a health promoting manner'* (13 p. 69).

*Nursing* – Nursing is mainly used in this thesis in the same manner as in Swedish municipalities; in conjunction with caregiving tasks that require a professional degree in nursing science (formal competence). A second option is that these tasks are performed according to a delegation from someone with formal competence based on her/his assessment of the competence the professional lacking formal competence, and who will perform the task, possesses. (delegations within professional care and nursing are regulated by Swedish laws and regulations, it does not apply to what is included in 'self-care' during informal caregiving).

*Life space* - 'Life space', should be understood as an individual's, or dyad's, holistic needs combined with her/his/their perceived capability to pursue needs that satisfy them (use SRRs/GRRs to acquire a 'fit' to derive a desired outcome). During Caregivinghood these life spaces encompass SRRs/GRRs and SRDs/GRDs in the domains.

*Older adult* – Is used as a 'label' for people aged 65 years and over, based on the customary retirement age in Sweden when the study was designed. It is used to distinguish this group from adults 18-64 years of age.

*Patient* – Patient is mainly used in conjunction with institutional settings and sometimes in homecare instead of ‘carerecipient’, depending on what terminology the references in this thesis use.

*Quality of life, QoL* – In this thesis Lindström’s salutogenic interpretation of the QoL-concept is used (14 p 43). This definition makes it possible to assess and describe QoL for separate individuals and describe what it is for this person in her/his context, but also take into consideration the outer context surrounding this individual’s specific context; ‘*Quality of life is the total existence of an individual, a group or society describing the essence of existence as measured objectively and perceived subjectively by the individual, group or society*’.

*Salutogenesis* – The word stems from Greek; *salus* (health) and *genesis* (origin) which means that salutogenesis is concerned with the origins of health. Conceptually, salutogenesis is defined as ‘the process of movement toward the health end of a health ease/dis-ease continuum’ (15). ‘*It is a way of thinking, being, acting and meeting people in a health promoting manner*’ (13 p. 20). Further, the meaning of Salutogenesis; ‘*Salutogenesis refers to a model of health, the sense of coherence and a life orientation*’ (16 p. 7). Epistemologically salutogenesis can be conceived as; ‘*a constant learning process supporting movement toward health*’ (17 p.92); knowledge about the meaning of salutogenesis, a way of relating to others and to be able to benefit from the knowledge and learning in everyday settings and life (17).

*Sense of Coherence, SOC* – The concept constitutes the core of the theoretical framework guiding this thesis. It is used to describe a general orientation to life construed out of peoples’ perceptions regarding their capability to understand, comprehensibility, and manage, manageability, the challenges they meet in interaction with their context. Meaningfulness is the motivational component that motivates them to invest the energy needed to manage what they have comprehended in a health promoting manner (10, 11, 13).

UT DESINT VIVES  
TAMEN EST LAUDANDA  
VOLUNTAS

ut = lit omu au  
desint = sakmas  
vives = kroftvna

tamen = likoil  
est = di  
laudanda = berreivrd  
voluntas = notyn

## INTRODUCTION

---

Main actors in this thesis are informal caregivers to older adults residing in an average, Swedish municipality, and the focus is their resources to health out of a salutogenic perspective. Demographic changes and an accentuation on home based community care contribute to increasing numbers of caregivers in most societies (4, 18-23). It is essential that they are willing to provide care, and that they are healthy enough to manage, not only for themselves and their care recipients, but also in terms of national welfare systems and economies. To preserve, if possible even enhance, their health is a prioritized challenge for homecare professionals, a reoccurring topic on political agendas and a focus in different research fields, but how this challenge should be met, is vividly debated. It could be met through the use of the traditional pathogenic approach, focusing on risk factors inducing negative outcomes and their elimination, or the salutogenic approach focusing on caregivers' resources to health and how they use these to derive positive outcomes. The latter poses an ethical dilemma for researchers, since the emphasis on negative outcomes have policy implications for the distribution of care and caregiver support (24).

A positive focus has been incorporated in caregiving research and a paradigm shift is emerging (25, 26), but the progress is slow and far less congruent knowledge exists regarding resources caregivers use to acquire positive outcomes, than regarding negative health outcomes associated with not being able to resolve them. This is unfortunate since health promotion conducted 'the salutogenic way' (focusing resources to health) indicates that people and systems adopting a salutogenic approach manage and endure stress better than those who do not (16, 27).

The theoretical framework, stipulates that all people experience stress in their life, but this does not automatically induce negative health outcomes. The outcome is dependent on how a person manages the challenges inducing tension (i.e. stress) they encounter; their tension management. How successful this tension management is, depends on the individual, contextual, material and immaterial resources they have at their disposal. These resources are labelled their *Specific and Generalized Resistance Resources*, *SRRs/GRRs*, whilst the hindrances they experience for using *SRRs/GRRs* are labelled *Specific and Generalized Resistance Deficits*, *SRDs/GRDs*. If a person can make sense of the stimuli she/he is constantly bombarded with in life (comprehensibility), are convinced that she/he has resources at their disposal to meet the demands induced by these stimuli (manageability) such demands are appraised as challenges that are meaningful to resolve (meaningfulness). Such persons have what Antonovsky called a strong *Sense of coherence*, *SOC*, which reflects a person's way of viewing life as structured, manageable and meaningful, an inner trust that leads people to identify, benefit, use and re-use the resources at their disposal (28); their *SRRs* and *GRRs*. Even if the associations between a strong *SOC* and positive health outcomes amongst caregivers is well known (29, 30) far less knowledge exist regarding the *SRRs/GRRs* and *SRDs/GRDs* influencing the strength of the *SOC*. This study was designed to unravel what these resources and deficits may consist of in a group of caregivers.

This thesis presents a frame including an introduction to the study's salutogenic theoretical framework, literature review, rationale, and aims for the study. Further the methodology, findings, discussion and conclusion are presented based on five papers. Paper I, presents the theoretical foundation and methodology and paper II-V present the SRR/GRR, SRD/GRD encompassed in the four domains in the synthesis of findings. 'Findings' presents this synthesis as a phase of life, *Caregivinghood*, and the core-theme; *Being situated in the duality of Caregivinghood*, which describes the caregivers' experiences during this phase due to the manner in which these experiences are influenced by 'SRRs/GRRs and SRDs/GRDs. In 'Discussion', findings are discussed in relation to how they may be used 'the salutogenic way' in clinical practice, health promoting initiatives and support development for caregivers. The plausible theoretical significance of findings, are also presented and discussed.



## THEORETICAL FRAMEWORK – SALUTOGENESIS

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Over 30 years ago, Aaron Antonovsky introduced the salutogenic framework as a complement to the pathogenic, which he considered more concerned with the studying of what generated ill-health, than health (10, 11). Several researchers during the late 1990s (24, 31, 32) may have harbored the same line of thought regarding caregiving research since they suggested a more holistic approach that could show both sides of the coin. In salutogenesis, health is viewed as a continuum stretching from *health ease* to *dis-ease* (10, 11, 13, 17, 33), implying that a person is always to some extent healthy. Antonovsky's approach when developing this theory was to ask the salutogenic question '*Why are people located towards the positive end of the health ease/dis-ease continuum, or why do they move towards this end, whatever their location at any given time?*' (11 p. xii), instead of the more traditional; Why do people get sick or develop diseases? His answer to the salutogenic question was the *Sense of Coherence*, SOC, construct. Antonovsky stipulates that the SOC is not a coping strategy to manage stress, but a general orientation to life construed out of peoples' perceptions regarding their capability to understand, *comprehensibility*, and manage, *manageability*, the challenges they meet in interaction with their context. *Meaningfulness* is considered the motivational component motivating people to invest the energy needed to manage what they have comprehended in a health promoting manner. Consequently, a strong SOC positions a person closer to health on the health continuum than a weak (11).

Prerequisites for a strong SOC are found in the salutary factors, the *Generalized Resistance Resources*, GRRs, which were defined when the theory was coined. They were described as material and non-material biological, cognitive, psychosocial and socio-cultural characteristics related to individuals, groups and environments (10-13, 27). GRRs are usable to combat a wide variety of *stressors* in life. In the salutogenic framework, stressors are viewed as the counterpart to resources, demands a person does not automatically know how to respond to. A *challenge* is the state of tension a stressor induces, whereas the outcome for a person depends on how the challenge is resolved by that person at that time, their *tension management* (11). The GRRs determine whether a person has access to individualized *Specific Resistance Resources*, SRRs, to resolve their challenges, thereby GRRs provide the prerequisites for successful tension management. Successful tension management creates *life experiences* characterized by '*consistency, participation in shaping outcome, and an underload-overload balance of stimuli*' (10 p. 187). Repetitions of such, in this thesis labelled 'positive' life experiences over time, nourish the SOC and induce movements towards health. Someone possessing a strong SOC may choose the most appropriate SRRs/GRRs to resolve challenges in a manner creating their desired outcome; they possess an inclination to cope with stressors (11). The key is not merely what SRRs/GRRs are available, but the person's ability to use and re-use them to resolve their challenges (28), or simplified their everyday problems, in a health promoting fashion.

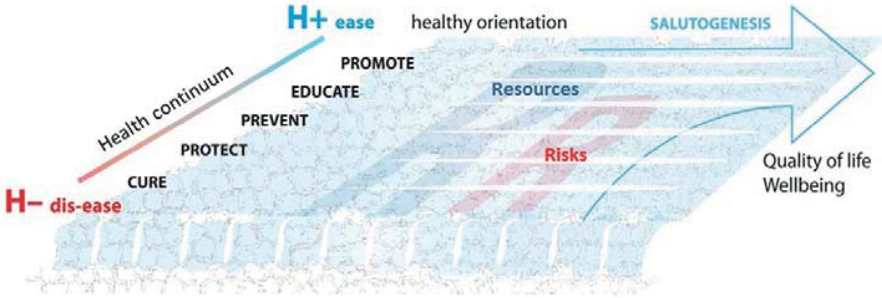
Depending on the context we are born into and how our lives evolve, we may find ourselves in life situations presenting disproportionate amounts of challenges in relation to the SRRs/GRRs we may use to resolve these challenges. Based on the extensive literature regarding difficulties, informal caregiving seems to be such a life situa-

tion, imbued by challenges, creating states of tension that caregivers have to use their tension management to resolve. Even caregivers possessing available SRRs/GRRs may perceive deficits making them unusable in tension management. According to the theoretical framework, this inability to resolve a multitude of challenges is, over time, likely to induce movements towards the dis-ease end on the health continuum. The theoretical framework (10, 11) is far less precise regarding the ‘mechanisms’ involved in these processes than regarding GRRs, but Antonovsky labelled these hindrances for successful tension management *Generalised Resistance Deficits, GRDs*, and stipulated that they ‘*provide experiences that vitiate one’s SOC*’ (11 p. 129), that is life-experiences ‘*characterised by inconsistency, under- or overload, and exclusion from participation in decision making*’ (11 p. 28). These life experiences are labelled ‘negative’ life experiences in this thesis and it was assumed that GRDs encompassed individualized *Specific Resistance Deficits, SRDs*, just like GRRs. In this thesis, experiencing hindrances for using available SRRs/GRRs as well as lacking the appropriate ones when managing tension, are included in ‘SRDs’ and ‘GRDs’.

Within the salutogenic framework stressors are not automatically viewed as pathogenic (i.e. inducing movements towards dis-ease), since the outcome depends on the affected person’s tension management (10). A stressor may thus, from hindsight even be viewed as health promoting, for example when having one’s first child or getting married, since such events hopefully moves the person closer to the health end of the continuum, even if the event may be stressful whilst it occurs (11). Coping is in this manner linked to the SOC, but Antonovsky viewed the frequently used theory of stress provided by Lazarus’ and Folkman’s (34) as stemming from assumptions about a homeostasis in life where a disturbance was assumed to damage health and wellbeing; the pathogenic view of life. Antonovsky stated that a homeostasis in life did not exist since everyone is living in some kind of chaos inducing tension. In the salutogenic framework, coping is seen as the internal perception of ability, based on comprehensibility, manageability and meaningfulness that enables a person to find the most appropriate way to react when a stimulus causing tension is appraised. In this manner, a strong SOC indicates an inclination, or global orientation, to cope with stress (11, 13, 35). However, a strong SOC also indicates that the person has access to usable SRRs/GRRs when managing tension induced by the challenges they encounter during their particular circumstances, in their particular context, such as when being an informal caregiver. Their tension management provides ‘positive’ life experiences since their challenges are resolved in concordance with their desired outcome (i.e. they ‘cope’). Repetitions of such positive outcomes over time ought to nourish their SOC and make it stronger, thereby the capability to use SRRs/GRRs is theoretically linked to movements towards health and quality of life.

Antonovsky uses the metaphor, ‘*The stream of life*’, in which we are all swimming to describe the complex mechanisms in the salutogenic theory. ‘*Wherever one is in the stream – whose nature is determined by historical, socio-cultural, and psychological environmental conditions – what shapes one’s ability to swim well?*’ (11 p. 90). Since Antonovsky first used this metaphor, it has further been developed and the stream re-labelled ‘*The river of life*’ (36). Placing caregivers within this river, I started to ponder upon the resources they use to ‘swim’ (SRRs/GRRs) and the ‘current’ they are

swimming against (SRDs/GRDs) in a river infested by challenges (shoals) they have to resolve throughout their caregiving experiences. The caregiving experience is complex, since the caregivers are not merely ‘swimming’ themselves in order to maintain some amount of health and quality of life, they are also helping their carerecipients to keep afloat. Or they are, at least, trying to prevent their dyads from sliding down the waterfall due to unresolved challenges induced by SRDs/GRDs interfering with their ability to swim (their use of SRRs/GRRs).



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Figure 1. Health in the river of life (36) used with permission

## LITTERATURE REVIEW

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When the study, upon which this thesis is based, was designed (paper I), there was a growing attention upon resources caregivers use to manage the complex, contradictory described situation of providing care (26, 31, 37-39). Homecare professionals knew from experience, that some caregivers managed better than others with, what appeared to be, similar amounts of burden, stress and other aspects inducing negative health outcomes. Even so, usable knowledge was lacking regarding *why* they managed better, which became the focus in the study; the content in caregivers' SRRs/GRRs and SRDs/GRDs.

The initial litterature review focused on the 'state of the art' in caregiving research, especially regarding positive aspects and particularly studies using salutogenic theory. Due to the sought concepts' theoretical functions (10, 11), it was expected they would be unravelled as internal characteristics (15) for example; applied strategies (40) gender (41) and relationships (20, 42). It was also expected to find external characteristics (15) for example reason for needing care (43) and aspects associated with the environment/context wherein caregiving was provided (44, 45). When the analysis of data was completed and Caregivinghood with its domains emerged, additional literature relevant for SRRs/GRRs and SRDs/GRDs encompassed in each domain was reviewed and added in each paper when the domains were presented (II-V).

Due to this procedure, the 'state of the art' in general caregiving research was not particularly updated after the initial review. Even so, it may be relevant to provide a description of 'the point of departure' for the study; a modified version of the initial literature review, complemented with some new additions to indicate the evolving diversification within the main areas in this thesis; informal caregiving research, health promotion and salutogenesis.

### Informal caregivers

Defining an informal *caregiver*<sup>1</sup> is problematic since they primarily have to define themselves as such according to their own values and norms (46). Even when they do, there is no guarantee that the caregivers are always regarded as such by others. These discrepancies depend on the context in which the term is used, by whom and the underlying intentions when defining 'caregiver' (e.g. economic, political, organizational). In this study, caregivers were defined according to a definition appropriate in a European context (4);

*'a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework'*

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<sup>1</sup>A multitude of 'labels' exist when referring to this population. In this thesis, the term 'caregiver' is used. If 'caregiver' refers to paid professionals 'formal caregiver' is used, the same applies to caregiving research. When referring to the cared for person, 'carerecipient' is used.

According to this definition, caregivers provide care in an informal setting, usually the carerecipient's home, wherein formal care workers sometimes are involved in the providence of care to the carerecipient. Caregivers are, according to the definition, essential for managing challenges related to someone else's health, quality of life and wellbeing, but caregiving also ought to include caring for yourself. Each caregiving situation is unique and involves, at least, two actors; the caregiver and carerecipient. In this study, these two as a unit were labelled the caregiving *dyad* (47, 48). The caregiver-carerecipient share the responsibility for how their dyad function, even if the caregiver is the main actor due to the carerecipient's functional limitations which affect her/his capability to contribute.

Demographic changes with ageing populations brings changes in societies, such as an emphasis on community care, which evoke concerns regarding whether there will be enough caregivers available to provide care to the increasing number of older adults (4, 18, 23, 49). Due to differences regarding how to define a caregiver, what is encompassed in caregiving vis-à-vis family obligations, welfare systems et cetera, it is impossible to estimate how many caregivers there are in different contexts. The more heterogeneous the scoop, such as a county's entire caregiver population (caregivers to persons from birth to death) or the entire European Union, the more unreliable the figures become (4, 19). Even so, there is a general trend that multiple factors collaborate to make caregivers a fast growing 'subculture' with specific needs associated to their health in most societies. Deteriorating health amongst caregivers may therefore be viewed as a challenging, potential public health problem that needs to be addressed. To meet these challenges, Zarit and Reamy (37) suggests that the predominant focus on '*caregiver stress, its antecedents and consequences*' (p. 157) should be replaced by a more dynamic approach which encompasses resources caregivers use to provide good quality care, without risking their own health and wellbeing over time, and also take the heterogeneity between situations and caregivers into account.

### **Informal caregiving research**

When informal caregiving became an issue in research and professional discourse in the latter part of the 1980s, caregivers' health was investigated mainly out of a pathogenic perspective, since being an informal caregiver was assumed to be a major stressful event hazardous to the caregiver's health. Consequently, the focus was on 'risk factors' inducing negative health outcomes. Concepts used in these early stages of caregiving research were subsequently such as anxiety, burden, depression, overload, strain and stress (50-53). Based on results from such studies, a multitude of interventions to reduce negative health outcomes were developed, used and evaluated (54-56). During the 1990s the focus on risks and negative health outcomes was challenged by researchers implying that there ought to be 'two sides to this coin'; positive *as well as* negative aspects associated with caregiving (24, 31, 32, 38, 50, 57). Even if earlier findings had been somewhat ambiguous, research in the positive field evolved to encompass a broader focus on psychosocial aspects such as wellbeing (58-60), occasionally in new ways and settings (61, 62). Studies designed to investigate both positive and negative aspects entered the scene (63-65), and the complex existential dimension of caregiving came into focus through concepts like meaning (40, 66) and quality of life (67, 68). The multitude of studies and the diversity of theories, instru-

ments and methods originating from multiple disciplines, made comparisons regarding both positive and negative aspects difficult. Caregiving research became so extensive and diversified that a comprehensive overview and some kind of consensus was almost impossible to attain and the pathogenic perspective still dominated, despite the more nuanced picture (23, 26).

### ***Specific focuses in caregiving research – an overview***

Amongst caregivers to older adults the most studied population is still caregivers to cognitively impaired carerecipients affected by dementia (39, 54, 69), although the interest in other groups of caregivers is increasing. Some of these groups are caregivers to carerecipients affected by amyotrophic lateral sclerosis, ALS (70-71); cancer (72, 73), heart failure (74, 75), multiple sclerosis (76, 77), Parkinson's disease (78, 79) and what may be the second biggest group; stroke (25, 30, 67, 80, 81-83). Most caregiving research is conducted in Western countries, mainly in the United States of America, Australia and Europe. As new geographical areas enter into the sphere of greying populations, caregiving research emerges from countries like Japan (62, 84), Taiwan (85), China (61, 86) and from so called developing countries (87-89). The caregiver experience has also been focused based on other caregiver characteristics, such as being a male caregiver (90-95), adult child caring for an aging parent/parent-in-law (20, 42, 96) or when the caregiver is an older adult her-/himself (97, 98).

Dyadic research involving both caregiver and carerecipient has evolved; how the relationship within the caregiving dyad is affected (48, 99-103) and intervention-studies have been designed to be beneficial for both the caregiver and carerecipient in the participating dyads (104-109). A special interest has developed regarding how environmental and contextual aspects influence the caregiver's situation and experience (18, 23, 44, 45, 110, 111). Caregivers' coping skills have always been in focus, as this seems to be a clue to why some caregivers experience a more positive journey. Subsequently, findings from this subfield in caregiving research has been used to design interventions, to find ways to assess caregiver needs and to decide whom may be best suited to meet them (56, 81, 112-118). Finally, during the last decade the more holistic research, focusing on positive as well as negative aspects, has established itself (114, 119, 120). Due to an enhanced focus on the caregivers' situations, different organizations and research groups have been founded internationally and nationally (4, 19, 21, 121-124). Main objectives for these organizations are to fend for caregivers' rights, develop programs to support caregivers, initiate research and to inform policymakers and others regarding issues related to informal caregiving.

Based on this overview, the main research areas during the 2000s seems to have been concerned with gender and relationship aspects, caregiving as a dyadic process, the caregiving experience in other groups and contexts than the previously focused, development of instruments and interventions, assessment of support needs and the allotment of support providence between formal/informal structures. Due to findings from such research, much has been accomplished to ease the caregivers' situations, but societies and researchers are still struggling to find even better ways. Quantitative studies using pathogenic approaches measuring negative aspects of caregiving, mainly amongst Caucasian caregivers to cognitively impaired carerecipients, still domi-

nate research even if the diversification is increasing. Cautiously, based on this review, it may be concluded that informal caregiving is mostly heavy work, complicated to assess and to ease and therefore hazardous to caregivers' health. Even so, some caregivers seem to find the journey through this phase of life when they provide care less of an ordeal than others, the unanswered question remains *why* and, subsequently *how* may their situation be eased and their health promoted?

### **Salutogenesis in informal caregiving research**

#### *The SOC and coping in caregiving research – quantitative designs*

Based on his answer to his salutogenic question, Antonovsky (11) developed 'the Orientation to life questionnaire' (abbreviated as SOC and a number indicating the included items, e.g. SOC-13, SOC-29) to measure the SOC. This questionnaire, and multiple variations of it, has been validated and used extensively in different contexts to study the SOC's relationship with different concepts, such as health and quality of life (28, 125). In caregiving research amongst older adults, most studies using the salutogenic framework are cross-sectional, have quantitative designs and utilize the SOC-questionnaire to measure caregiver's coping capability.

According to Coe, Miller and Flaherty (126) only two previous studies had used the SOC-questionnaire amongst older adults (127, 128), neither focused on caregivers. Coe et al. (126) examined perceived burden amongst 148 caregivers to chronically ill older adults recruited from 22 programs delivering different services to older clients, regardless of the carerecipients' impairment or disease. Even if the study is from 1992 results from this pioneering work regarding the SOC and caregiving, are mainly in concordance with results presented from general informal caregiving research, and caregiving research using salutogenic theory, conducted during the decades that have elapsed. For example, Coe et al. (126) found that caregiving men had stronger SOC than caregiving women (41, 129), higher morale, lower levels of depression, were better integrated in family support systems/friendship networks and perceived that they presently needed little or no for further help. Such finding distinguishing caregivers with a strong SOC from those with a weak, have later been found as essential contributors to positive aspects associated with caregiving in multiple studies.

Regarding burden, one of the major negative effects studied in caregiving research, Coe et al. (126) showed an inverse relationship between the SOC and caregiving burden, for all conditions, except urinary incontinence. When confounding factors were accounted for, *maintaining* continence was related to burden. In line with later findings this indicated that the experience of burden seemed more related to caregiver characteristics (e.g. SOC) and caregivers' efforts to prevent problems, than to carerecipients' functional level and care needs (67, 130). Coe et al's (126) findings regarding the buffering aspect of a strong SOC in relation to burden and perceptions of needing more support, have later been well documented using burden and similar concept (43, 82), stress and psychiatric morbidity (131) and general health measured at a biomedical level (129). Longitudinally, the association between a strong SOC and low levels of negative aspects, such as depression, have been found persistent over two years of caregiving (82).

Gallagher et al. (43) found that a strong SOC buffered against overload among dementia caregivers. They implied that this may be due to caregivers' use of cognitive coping (i.e. meaning, learning), since non-dementia caregivers used other forms of coping, mainly more situation specific (i.e. directing patient behavior) and had a higher impact of functional limitations on overload than dementia caregivers had. These results suggested that the meaningful component in the SOC (dementia caregivers' coping) was more essential for the SOC than the manageability component (non-dementia caregivers' coping), which is in concordance with the theoretical framework (11). Mockler et al. (131), found that non-users of mental health services had higher SOC-values than service users which implied better ability to cope, presumably due to the presence of salutary factors. Zhang et al. (129) found that caregivers with stronger SOC experienced more positive and less negative aspects associated with caregiving, than those with low values. The authors suggested that the higher SOC may indicate that these caregivers perceived their stressors as less of a threat and more of a challenge and that they may have had greater confidence in possessing the required coping resources. Thompson et al. (41), suggested that different approaches to the caregiving role may be one explanation to why caregiving women had lower SOC-values and more manifested symptoms of chronic stress than men. Social support seemed to buffer against low SOC-values in a population based sample (132). These findings may indicate a better capability to cope, as the presence of social support is an essential GRR for acquiring a strong SOC (11). Caregivers' coping ability, measured by SOC, have also been found to have a significant impact on caregiver's quality of life (67).

In Sweden, a group of caregivers to stroke survivors, the SOC was found to equal a Swedish population sample during the first acute phase and there were no sex or age differences regarding the SOC in this group (133). Initially Forsberg-Wärleby et al. (133) found coping ability and the appraisal of future life situation, significantly related to psychological wellbeing, but not to objective state of impairment. The association between objective impairment and caregiver SOC did not change over time, but a higher SOC was associated with higher satisfaction with life in general, closer relationships, a better financial situation, a brighter view of their partner's future health and their own coping capacity (133). These finding seem to be in concordance with Van Puymbroeck's and Rittman's (67) assumption that the coping capacity amongst caregivers to stroke survivors during the early phase, is more related to caregiver traits than to carerecipient characteristics (*ibid*; their SOC). The striking differences between couples and within dyads regarding how they appraise their situation, may explain why individuals with low SOC had greater difficulties coping and an increased risk of burnout, regardless of whether they were caregivers or carerecipients (80). Such findings are in concordance with the salutogenic framework, since they presumably indicate a shortage of usable SRRs/GRRs, or the presence of SRDs/GRDs, when facing challenges during caregiving.

Two study-groups in the longitudinal survey The Swedish National Study on Ageing and Care, SNAC (134), have used the SOC questionnaire amongst caregivers. According to Andrén and Elmståhl (29, 135) a strong SOC was related to less burden and better subjective health than a weak in two slightly different groups of caregivers to older adults with mild dementia and a high degree of independence. The authors



stated that caregivers with a weaker SOC found the situation less comprehensible, more difficult to manage and less meaningful, implying that they had fewer resources to apply in their situation and therefore experienced negative health effects (29). Kristensson Ekwall and Rahm Hallberg (136) studied associations between gender, extent and content of care, satisfaction, coping and difficulties in the caregiving situation. Even though men and women had comparable SOC-values, men found more satisfaction in caregiving than women did. The conclusions were that women may be less protected against the negative aspects of caregiving than men, and that those who found most satisfaction used more problem focused coping than others (136). Using the same population in another study, a strong SOC was associated with high mental quality of life and more self-sustaining coping strategies (137).

The SOC questionnaire has been used extensively with the direct purpose of assessing caregivers' coping capability, frequently resulting in recommendations to design interventions to strengthen caregivers' SOC (82, 129, 133). However, such usage may be questionable since the SOC encompasses much more than coping capability, and using the SOC-scale is not the same as being guided by the SOC-vision (138, 139). Antonovsky (11 p. 63) stated that he was '*one whose career had largely been in survey research*' as the reason for using a quantitative approach when constructing the SOC-questionnaire. He also stated that he would be delighted if qualitative approaches and techniques were applied to the salutogenic question. It can only be speculated regarding what Antonovsky may have thought such a development could unravel regarding what SRRs/GRRs and SRDs/GRDs involved in processes affecting the strength of the SOC, may consist of. The importance of having access to resources, and not experiencing hindrances for using them, is discernible in studies using the SOC-questionnaire to study caregiver coping. Even when suggesting that caregivers should cope better if their SOC was strengthened, these quantitatively designed studies are restricted to rely on variables they have measured to reach this conclusion. Thereby, they rarely provide enough data, regarding the content in what may be considered the participants' SRRs/GRRs and SRDs/GRDs influencing their SOC, to be able to suggest *how* such a strengthening of their SOC may be acquired.

#### *Salutogenesis amongst caregivers – qualitative or mixed designs*

Qualitative designs frequently use more or less open-ended interviews to collect data. Thereby a topic is illuminated through the participants' own eyes and not restricted by variables and hypothesis pre-determined by a researcher or research groups. In the mid-2000s studies using qualitative methodology and salutogenic theory among caregivers to older adults were scarce. Milberg and Strang (140, 141) used the salutogenic framework as a theoretical foundation when studying facilitating as well as burdensome aspects amongst caregivers to patients enrolled in palliative homecare. Through the use of this framework, the authors derived an understanding they assumed another approach would not have acquired and stated that this understanding was essential for the development of palliative homecare services (142). At that time, Milberg and Strang were the only authors who had used the salutogenic framework inductively in combination with qualitative methodology to unravel GRRs amongst caregivers to older adults in Sweden. The SOC had been used to discuss findings from other Swedish studies amongst caregivers (143, 144), but they did not present GRRs. Stud-

ies involving caregivers to older adults utilizing mainly qualitative methodology and salutogenic theory outside Sweden, were rare and mainly concerned with particular populations of caregivers (73, 87, 93). Most of these studies utilized the salutogenic framework to code and present findings.

When the study for this thesis was designed, only two studies altogether were found that presented caregivers' GRRs. Potgieter and Heyns (87), who did not intend to unravel GRRs, found factors that '*made a clear contribution to the caregivers' ability to successfully manage the stressors associated with caregiving*' (p. 558) during the qualitative part of their analysis. These factors were presented as the GRRs *support-seeking, remaining future-oriented* and *religiosity*. Milberg and Strang (142) developed a theoretical framework concerning family members' experience of palliative homecare staff based on a secondary analysis of four previous studies. They presented five GRRs related to staff input; *competence, support, spectrum of services, continuity and accessibility* and two to staff-interaction; *being in the centre and sharing caring*. They also described six health-disease continuums influencing the emotional and existential consequences of family members' experiences; *Security-Insecurity, Hope-Hopelessness, Togetherness-Isolation, Self-transcendence-Insufficiency with guilt and/or anger, Congruent inner reality-Chaos, Retaining everyday life-Disruption of everyday life* (142). When the review of caregiving literature for the study in this thesis was made, only a few studies presenting GRRs were found and none presenting SRRs, SRDs or GRDs.

## **Health promotion, older adults, caregivers and the salutogenic approach**

Havighurst (145) was one of the first gerontologists to change the focus towards positive aspects in ageing through the use of the concept 'adding life to the years'. He related this concept to the gerontological mission and explained it as '*helping people to enjoy life, and get satisfaction from life*' during the latter part of it (p. 8). He also argued for the necessity to have a theory of successful aging to proceed with this mission. It may be implied that Havighurst's (145) initial intention with linking 'adding life to the years' to the gerontological mission became lost over time. The manner in which 'successful aging' became a focus in gerontological research caused a vivid debate regarding its appropriateness due to the negative aspect it seemed to induce, such as elitism and ageism (146). Keeping this debate in mind, aspects associated with 'successful aging' has been investigated by a range of researchers (147-149) have widened the focus and provided knowledge for longitudinal studies (149-154).

The initial intention with the concept 'adding life to the years' seem to have influenced the development within health promotion for the increasing amount of older adults and the development of policies, during the last decades (155, 156). International policy documents use key concepts such as independence, participation, dignity, care and self-fulfillment to provide health promoting contexts for *all* older adults (8). This ought to encompass the majority of caregivers providing daily care to older adults with long-term care-needs, at least in Sweden (18 p. 80-83), since such caregivers are usually old spouses, close friends or children who are, or soon will be, older adults themselves. Positive concepts describing aging are active ageing, healthy aging, suc-

cessful aging, positive aging (157) and lately resilient ageing linked to the salutogenic theory in a manner that provides implications for nursing and policy development (158). The WHO policy framework Active Ageing (8) describe determinants for Active ageing (p. 19) and has been used to form a WHO resolution to strengthen active and healthy ageing (159). It is important for healthy aging that people have the possibility to age in place, which is described as '*the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income or ability level*' (160). This means that older people, such as most caregivers to older adult carerecipients, receive adequate support and that their caregiving may be provided in age-friendly communities (157). In such communities, these dyads may be active participants regardless of carerecipients' functional deficits and impairments (161, 162).

Essential concept determinants encompassed in the previous paragraph, implies that the responsibility to promote older adult health rests on multiple societal levels, not merely the healthcare sector, even if homecare professional in Sweden usually work closest to older adults, at least those with long-lasting care needs and their caregivers (18). Traditionally nurses have focused on ill health, but during the last decades a new, or renewed, professional approach when engaging in health promotion have been suggested by nursing researchers. These researchers imply that professionals prepared to take this step have to orientate themselves more towards health than ill health, re-evaluate their professional roles and emphasize that of health promoters in a wide sense at society level (9, 158, 163-165). Techniques exists that professionals may use to focus on health resources in dialogues with patients and families (166-169). Aspects associated with how professionals may focus on resources to support positive health development when working with caregivers in community settings, have also been focused (170-174). Even so, the shift of paradigm caregiving researchers have asked for since the late 1990ties is slow and the pathogenic approach still dominates the research field (25, 26).

The theoretical underpinnings of health promotion originate from the biomedical perspective's pathogenic approach wherein health was a goal, viewed dichotomously as healthy/not healthy. Today, health promotion is considered the process that enables individuals and communities to use their resources to increase control over their health determinants, thereby enabling them to live qualitatively good lives (7, 8, 175). Health is considered a resource for everyday life and a salutogenic approach, viewing health as a continuum ranging from health ease to dis-ease, has been suggested as the most fruitful way to advance theory and practice towards *population health* (12, 27, 138, 175). If caregivers to older adults are viewed as a population in this regard, empirical work using the salutogenic approach should focus on caregivers' resources to health as a population in a communal context (e.g. an ethnical group, a municipality, a nation). This reasoning indicates that a salutogenic approach may be more fruitful when gathering necessary data upon which to build homecare, health promoting initiatives, policies and support for caregivers at different levels (27, 158).

## RATIONALE

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Caregiving research has shown that informal caregiving is hard work that takes place in a specific context and that this context combined with individual caregiver-, care-reipient- and circumstantial characteristics influence how the caregiver seem to experience her/his situation.

This situation is complicated to assess and the last decades of research has also shown that there are two sides to this coin; positive as well as negative outcomes and experiences. However, the approach in caregiving research has mainly been pathogenic and focused on negative outcomes and risks in order to develop interventions and support that minimize negative effects on caregivers' health. Such interventions are important since caregivers' health, thereby their ability to provide care, is essential worldwide due to increasing numbers of care-recipients in need of informal care. Even if there is less congruence regarding why, some caregivers seem to experience their situation more positively than others which indicates that they have access to resources that are beneficial for their maintenance of health, quality of life and wellbeing.

The salutogenic theory focusing on a person's ability to comprehend, manage and find it meaningful to invest the energy needed to manage challenges they encounter in life, their SOC, have been used extensively and validated in empirical research. Amongst informal caregivers to older adults, the main utilization has been to measure the SOC in different constellations of caregivers to compare their SOC-values with their coping capability since a strong SOC is associated with better coping and less negative health effects. Qualitative research using salutogenic theory amongst caregivers to older adults exist, but have mainly been concerned with finding the three SOC-dimensions in interviews and narratives. The salutogenic framework explains the function of GRRs and GRDs and how they, through life experiences derived from a person's tension management, affect the strength of her/his SOC and thereby their movements along the health ease dis-ease continuum. Even so, GRRs and GRDs were described decades ago and little attention has been paid to evolve upon them any further. Consequently, knowledge regarding what they may consist of in societies of today is scarce, and especially not derived through studies using qualitative designs wherein the study population may describe this themselves. Since Antonovsky stated that progress regarding the salutogenic theory would only be made through the use of different methodologies, the qualitative approach regarding GRRs needs to be further reinforced in general.

Based on the literature review for this study there seems to be a specific need to identify caregivers' SRRs/GRRs and SRDs/GRDs to complement quantitative findings regarding their SOC-values. Such knowledge may be used empirically by professionals working with caregivers and to design health promoting initiatives and support that may preserve, or even enhance, caregivers' health the 'salutogenic way'. The study was designed to derive congruent knowledge concerning what informal caregivers' Specific and Generalized Resistance Resources, SRRs/GRRs and Deficits, SRDs/GRDs, may consist of, and suggest how such knowledge may be used to promote their health.

## AIMS

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### Overall aim

To derive congruent knowledge concerning what informal caregivers' Specific and Generalized Resistance Resources, SRRs/GRRs and Deficits, SRDs/GRDs, may consist of and suggest how such knowledge may be used to promote their health.

### Specific aims

- Paper I* To describe how the approach derived from the salutogenic theory was used and how it permeated the entire study from design, data collection and analysis to findings. A further aim was to discuss how participating in a study using this approach was experienced and how the methodology may be improved.
- Paper II* To present Generalized and Specific Resistance Resources (GRRs/SRRs) described by caregivers as stemming from themselves and their carerecipients.
- Paper III* To present Specific and Generalised Resistance Deficits (SRDs/GRDs) described by caregivers as stemming from themselves and their carerecipients.
- Paper IV* To present Specific and Generalized Resistance Resources (SRRs/GRRs) and Deficits (SRDs/GRDs) described by informal caregivers as originating from the caregiver and carerecipient as a dyad.
- Paper V* To present Swedish informal caregivers' environmental and contextual resistance resources and deficits (the EC-domain of Caregiving-hood) and how the generated knowledge may contribute to the development of health promotion initiatives.

## METHODOLOGY

The study was thoroughly embedded within the realms of the salutogenic theory of health as it was described by Antonovsky (10, 11), and the theoretical foundation and methodology has been presented (I). It was designed to derive congruent knowledge concerning what informal caregivers' Specific and Generalized Resistance Resources, SRRs/GRRs and Deficits, SRDs/GRDs, may consist of, and suggest how such knowledge may be used to promote their health (Table 1).

**Table 1.** Overview of the study

	Paper I	Paper II	Paper III	Paper IV	Paper V
<b>Design</b>	Theory-driven, explorative and descriptive	Descriptive	Descriptive	Descriptive	Descriptive
<b>Participants</b>	32 volunteering, primary caregivers to older adults residing in the same, Swedish municipality (I-V)	-	-	-	-
<b>Data collection</b>	Interviews; qualitative and quantitative data (I-V)	-	-	-	-
<b>Aim</b>	A - To describe how the approach derived from the salutogenic theory was used and how it permeated the entire study from design, data collection and analysis to findings. B - To discuss how participating in a study using this approach was experienced and how the methodology may be improved.	To present Generalized and Specific Resistance Resources (GRRs/SRRs) described by caregivers as stemming from themselves and their carerecipients.	To present Specific and Generalised Resistance Deficits (SRDs/GRDs) described by caregivers as stemming from themselves and their carerecipients.	To present Specific and Generalized Resistance Resources (SRRs/GRRs) and Deficits (SRDs/GRDs) described by informal caregivers as originating from the caregiver and carerecipient as a dyad.	To present Swedish informal caregivers' environmental and contextual resistance resources and deficits (the EC-domain of Caregivinghood) and how the generated knowledge may contribute to the development of health promotion initiatives.
<b>Data analysis</b>	A-Theory-driven, mainly qualitative, inductive within-case and deductive across-case analysis (I-V) B-Qualitative content analysis (I)	-	-	-	-

Due to the theoretical framework, the focus of attention in this study was on caregivers' tension management, wherein SRRs/GRRs and SRDs/GRDs are essential for the outcome. A salutogenic approach was used to explore how informal caregivers in a Swedish medium sized municipality described their situation to be able to unravel the resources, SRRs/GRRs, they used to resolve challenges to derive a positive outcome and the hindrances for using them that they experienced; their SRDs/GRDs. Subsequently, the study became multifaceted since a variety of aspects in their situations had to be addressed to acquire data.

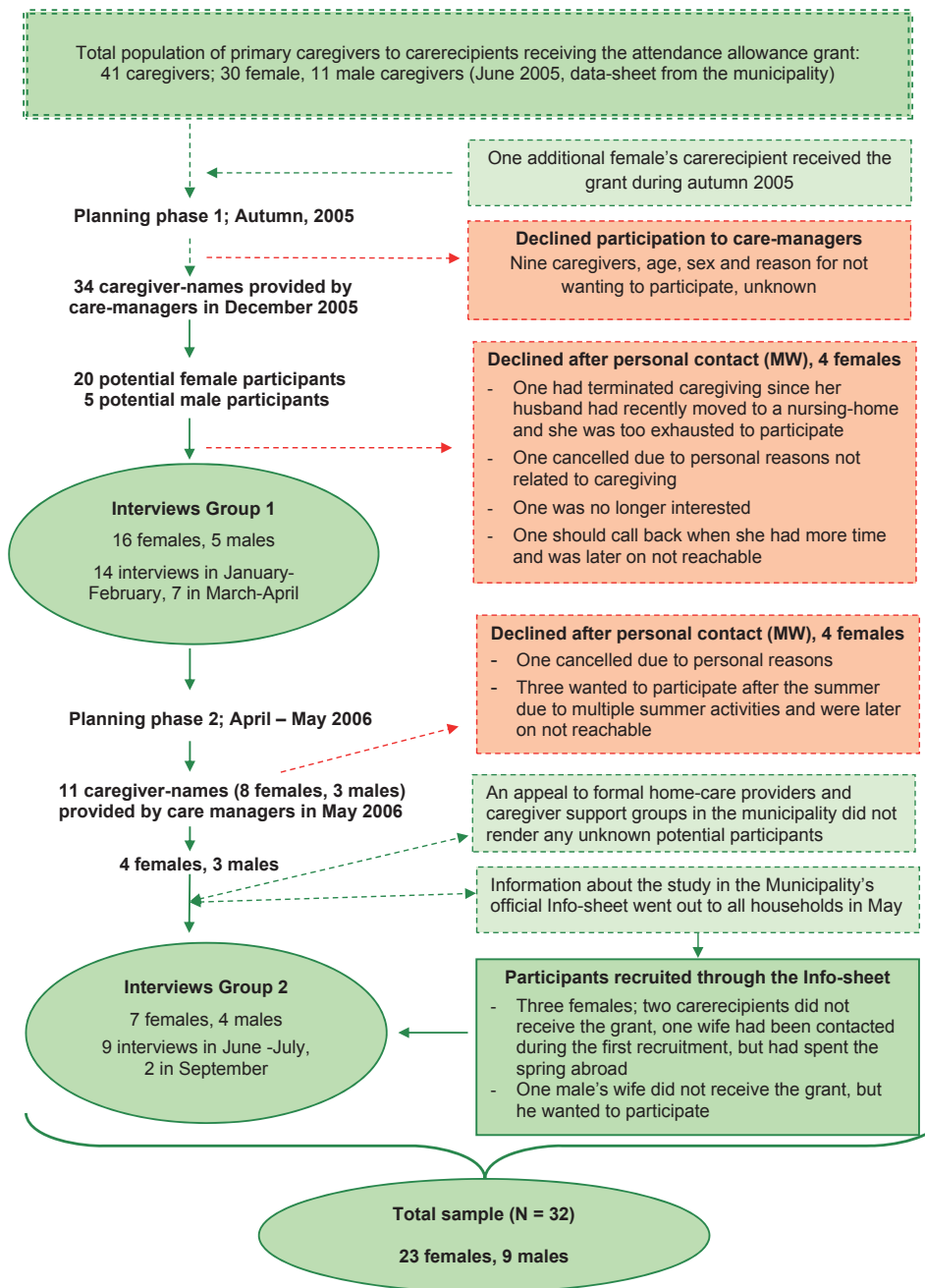
The correlation between a strong SOC and health has been thoroughly investigated and summarized (13, 176), however little attention has been paid to further elaborate on GRRs since these were defined 30 years ago, and even less attention has been paid to SRRs, SRDs and GRDs. Based on the theoretical framework and the literature review, some assumptions could be made regarding the design:

- SRRs/GRRs are ‘characteristic’ that through successful tension management provides ‘positive’ life experiences that ought to nourish caregivers’ SOC and thereby induce movements towards the health-end on the health ease/dis-ease continuum, or at least enable them to preserve their current position (Figure 1 p 19).
- SRRs/GRRs may be unravelled if caregivers are salutogenically approached and their reasons attached to *why* some aspects in their situation are positively described and *how* their intentions and motives for managing in their unique manners are explored.
- SRRs/GRRs may also be unravelled if reasons for *not* being able to manage in a specific manner is explored, since reasons and consequences for unsuccessful tension management creating ‘negative’ life experiences indicate which SRRs/GRRs the caregiver is unable to use and why.
- SRDs/GRDs ought to be unravelled in the previously described manner together with SRRs/GRRs even if the focus in the study is salutogenic, since a person describing *how* they manage usually adds; ‘but sometimes this is not possible because....’ to provide a sincere description.

To capture the essence in caregivers’ descriptions within-case analysis at an individual level was essential, but also the use of comparative techniques ‘*to produce contextually grounded generalizable findings*’, that is across-case analysis to unravel GRRs and GRDs at a communal level (177 p. 871) through ‘*finding the findings*’ in the caregivers’ descriptions (178). According to Antonovsky (10) GRRs (and presumably SRRs, SRDs and GRDs, *ibid*) could be material, immaterial, individual and contextual, indicating that apart from qualitative descriptions quantitative contextual data would be needed to understand why some characteristics could function as SRRs/GRRs and SRDs/GRDs.

## **Study context**

Due to the heterogeneousness of Swedish municipalities, data was collected in one municipality to minimize contextual biases (e.g. differing support systems, geographical prerequisites etc.). This municipality was versatile enough to contain a variety of characteristics that previous research indicated as potential, contextual SRRs/GRRs. It was rich in recreational areas, such as accessible tracks in nature, and had six population centres scattered over the area indicating reasonable distances to different services. The municipality was also located close to a major city region, indicating that the inhabitants had access to essential, shared features such as a large public transportation system and cultural arenas, and it did not deviate too much from the National average, regarding different variables (179). Some deviations did exist; the area was smaller, but the number of inhabitants equal to National means. Demographically, it was a municipality from which people commuted into a major city centre to work and thus had a ‘young’, continuously growing population with a proportion of 65+-year olds slightly lower than National means. Approximately 90% of the population lived in an urban setting and 75% resided in detached or semi-detached houses with gardens, in or close by, a population center.



**Figure 2.** The recruitment process (modified version from paper II).



## **Participants - The recruitment process**

The intention was to recruit as many caregivers as possible caring for someone aged 65+ years living at home in this municipality, regardless of other variables such as age, gender or relationship. Excluded were only caregivers enrolled in the end-of-life program (2-5 annually) since these situations are fairly short term and differs considerably from other caregiving situations.

To reach self-identifying caregivers (46), a specific type of economic support system was used that usually encompass information regarding the primary self-identifying caregiver to carerecipients receiving this type of support. This system is called 'the attendance allowance'. It is optional for the Swedish municipalities to use it, and the number that do is decreasing (5, 180). This allowance is granted the carerecipient based on an assessment of the her/his care need conducted by a care manager, who is an official with specific responsibilities in a municipality's care organization (5 p. 13).

Forty-two carerecipients in the chosen municipality received the allowance in 2005<sup>2</sup>. After obtaining permissions to conduct the study from the municipality's politicians and the head of the elder-care sector, the care managers contacted the primary caregivers and informed them orally in broad terms about the study. If they wanted further information, they were referred to the primary investigator (the author of this thesis) who provided detailed information regarding the study, emphasizing that it was a doctoral project conducted by a homecare nurse without professional ties to this municipality. They were also informed regarding practical and ethical procedures (181) and asked if they needed formal support during the interview, which two caregivers did.

Practical arrangements were made with caregivers who decided to participate and the provided oral information was sent in writing to each participant together with time and location for the interview (I). Due to unclear reasons, a caregiver to a carerecipient aged 63 years had been contacted and wanted to participate and she was included. The recruitment process of 32 participants is described in Figure 2.

### ***Caregiver and carerecipient characteristics***

Data describing the participating caregivers, their carerecipients and the environment/context in which caregiving was provided, mainly originate from a questionnaire; the 'Demographic Salutary Questionnaire, DSQ', designed to assemble quantitative data considered necessary to unravel SRRs/GRRs and SRDs/GRDs (Supplement in paper II). Some explanations from qualitative data have been added in the following sections to provide a fuller description of the caregivers, carerecipients and their shared context, and to exemplify how qualitative and quantitative data interacted during the analysis.

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<sup>2</sup>In 2004 the chosen municipality endorsed the attendance allowance at two levels; lower level based on a care need of 7 – 14 hours/week rendered ~200 Euro/month; higher level based on a care need of 15 hours or more/week rendered ~300 Euro/month.

**Table 2.** Caregiver characteristics (modified version from paper II and V)

<b>Caregiver characteristics</b>	<b>Wife (n=17)</b>	<b>Husband (n=9)</b>	<b>Daughter (n=6)</b>	<b>Total (N=32)</b>
<b>Age</b>				
Mean	71	78	58	71
Median (Range)	71 (60-84)	79 (67-87)	58 (50-69)	72 (50-87)
<b>Civic status</b>				
Married	17	9	5	31
Single	0	0	1	1
<b>Family situation</b>				
Have no children/grandchildren	1	0	2	3
Have Children	16	9	4	29
<b>Number of years as caregiver</b>				
Mean	9	8	6.8	8.3
Median (Range)	5 (2-31)	7 (3-20)	6.5 (3-12)	6 (2-31)
<b>Co-habit with carerecipient (years)</b>	(n=17)	(n=9)	-	Mean 49 Range 16-65
<b>Main occupation (vocational identity)</b>				
Craftsman or industrial worker	2	6	0	8
Educational sector	3	0	0	3
Self-employed or 'housewife'	2	1	0	3
Service profession including care/nursing	10	2	6	18
<b>Have professional care/nursing experience (incl. main occupation)</b>				
Mean (Range) years	9 11 (0.5-30)	1 1 (1)	4 10 (0.5-25)	15 10 (0.5-30)
<b>Physical health (self-rated)<sup>1</sup></b>				
Much	4	1	0	5
Better	2	5	3	10
Equal	8	3	2	13
Worse	3	0	1	4
Much Worse	0	0	0	0
Mean	Better	Better	Better	Better
Change since becoming a caregiver	Unchanged	Worse	Better	Unchanged
<b>Psychological health (self-rated)<sup>1</sup></b>				
Much	2	0	0	2
Better	4	4	1	9
Equal	8	4	4	16
Worse	3	1	1	5
Much Worse	0	0	0	0
Mean	Better	Better	Equal	Better
Change since becoming a caregiver	Worse	Worse	Unchanged	Worse
<b>Contentment with general health (Range: Content – Discontent)</b>	Fairly content	Fairly content	Fairly content	Fairly content

<sup>1</sup>During ratings, caregivers made comparisons towards other persons their age

All spouses co-habited, daughters only with their mother if her health required it (one interview). Two daughters lived in adjacent municipalities (distances to mothers; Mean 7, Range 0.2-30 km) and two daughters were older than the three youngest spouses. Of the eighth caregivers who had extensive caregiving responsibilities for more than one carerecipient, four assisted adult, impaired children who lived close by and needed daily/almost daily assistance, one daughter had young children and a grandchild living with her, two wives assisted aging mothers, one a disabled sibling. Fifteen caregivers had professional care/nursing experience (Table 2), whereof four had worked over 25 years as formal caregivers to older adults, an additional four had previously been informal caregivers (parents, sibling).

To be able to understand why some aspects in the caregivers' situations became challenges, it is essential to have knowledge regarding the carerecipient. Seventeen carerecipients were husbands, nine wives and six mothers (Table 3), two mothers were younger than the three oldest spouses. Like most carerecipients who are known to the officials in a Swedish municipality, these carerecipients needed care due to a wide variety of functional limitations, some had a diagnosis, some did not according to the caregivers. Eleven carerecipients had three or more physical conditions, frequently in combination with psychological conditions. Some caregivers suspected their carerecipients were affected by dementia, even if they lacked a diagnosis. Other caregivers spoke about behavioral problems that may be due to dementia, but could also be due to psychiatric morbidity, or other reasons inducing excessive anxiety. All these conditions were grouped together as 'psychological impairment' since they induced the same type of care needs (Table 3). Fourteen carerecipients had difficulties to communicate due to aphasia and/or extensive loss of sight or hearing, some in combination with psychological impairments, which made it difficult for their caregivers to discern which was an effect of what.

The three women who managed/almost managed by themselves were mothers who were alone most of the time. Two received daily home help (morning/evening), all had safety-alarms. All carerecipients, except one of the oldest mothers, needed daily care. Twenty-five of these needed extensive assistances with multiple ADL-tasks, whereof nine received daily home help (Table 4). Seven carerecipients had severely impaired loneliness-capability, some in combination with memory problems. Five mothers never or rarely had memory problems, whilst one had it all the time. This mother was in adult day care during week-days, had frequent visits from her daughter during other hours and somehow managed to spend her nights alone, according to her daughter.

### ***Environmental and contextual characteristics***

In the salutogenic theory *context* matters, since SRRs/GRRs and SRDs/GRDs may be found within the individual as well as within their environment and context. To be able to unravel SRRs/GRRs and SRDs/GRDs, DSQ encompassed questions associated with the environment and context in which caregiving took place. For example, the number of carerecipients living in adapted facilities, caregivers' capability to transport themselves and their carerecipients to places they usually frequented, as well as data regarding formal and informal support. Some of the assembled characteristics are shown in Tables 4 and 5.

**Table 3.** Carerecipient characteristics (modified version from paper II and V)

<b>Carerecipient characteristics</b>	<b>Women (n=15)</b>	<b>Men (n=17)</b>	<b>Total (N=32)</b>
<b>Mean age (range) in years</b>	Wives 77 (67-86) Mothers 89 (76-97)	76 (63-86)	77 (63-97)
<b>Physical disease or impairment inducing the need for assistance</b>			
None	4	1	5
One to two	7	9	16
Three or more	4	7	11
Stroke or other cerebral injury	3	9	12
Heart condition	3	5	8
Diabetes	0	4	4
Neurological disease (MS, ALS, Parkinson's)	4	0	4
Chronic catheter user (regardless of reason)	0	4	4
Rheumatoid arthritis	3	0	3
Respiratory disease	1	1	2
Status, post unsuccessful operation	0	2	2
<b>Extensive difficulties to communicate<sup>1</sup></b>			
Stroke/other cerebral injury severely affecting speech	4	3	7
Psychological impairment incl. psychiatric morbidity, excessive anxiety and dementia	11	10	21
Blind, deaf or extensive limitations with sight/hearing	2	5	7
<b>General decline due to ageing</b>	4	0	4
<b>Social deficiencies (loneliness, behavioral problems)</b>	7	3	10
<b>Frequency for needing assistance</b>			
Always day and night	2	2	4
Frequently day and night	7	13	20
Couple of times a day	5	2	7
Couple of times a week	1	0	1
<b>Capability in activities for daily living (ADL)</b>			
Manages her-/himself	1	0	1
Manages everything except showering or walking outside	2	4	6
Needs help with showering	12	16	28
Needs some assistance with multiple tasks	10	6	16
Needs complete assistance with all ADL	2	7	9
<b>Mobility</b>			
Manages her-/himself	7	7	14
Needs assistance outside	5	5	10
Needs assistance with all ambulation	3	5	8
<b>Loneliness capability</b>			
Never	1	0	1
Short periods of time (if caregiver goes to basement, into the garden etc.)	3	3	6
A few hours	5	13	18
Always, except when needing what caregiver provides	6	1	7
<b>Memory problems</b>			
Never	8	13	21
Seldom (1-2 times a week, under particular circumstances)	2	2	4
Often (3-6 times a week)	1	0	1
Very often (several times a day)	4	2	6

<sup>1</sup>Several carerecipients had a combination of these conditions affecting their ability to communicate

**Table 4.** Caregivers' formal and informal support (modified version from paper V)

Caregivers' formal and informal support	Wife (n=17)	Husband (n=9)	Daughter (n=6)	Total (N=32)
<b>Emotional support (availability)</b>				
always available	13	6	5	24
usually	1	0	1	2
sometimes	1	0	0	1
rarely	0	1	0	1
never	2	2	0	4
Primary provider; family	14	7	6	27
Secondary provider; formal care	6	3	3	12
One provider	7	3	0	10
<b>Emotional support (contentment)</b>				
completely content	9	4	4	17
almost	6	1	1	8
neither/nor	0	1	1	2
rather discontent	0	3	0	3
very discontent	2	0	0	2
<b>Practical support (availability)</b>				
always available	12	9	4	25
usually	2	0	1	3
sometimes	1	0	1	2
rarely	2	0	0	2
never	0	0	0	0
Primary provider; family	11	6	6	23
Primary provider; Formal care	4	1	0	5
Secondary provider; formal care/family	4	1	0	5
One provider	4	1	1	6
<b>Practical support (contentment)</b>				
completely content	7	4	2	13
almost	6	4	1	11
neither/nor	2	0	3	5
rather discontent	1	0	0	1
very discontent	1	0	0	1
(One man could not provide an answer)				
<b>Receives regular assistance in caregiving from partner, child or sibling</b>	1	2	5	8
<b>General contentment with total social situation (informal support, contacts with family/friends)</b>				
completely content	7	5	0	12
almost	5	2	5	12
neither/nor	2	1	0	3
rather discontent	2	1	1	4
very discontent	1	0	0	1
<b>Granted formal support at the workplace (regardless of who was granted support)</b>				
Home help (daily help)	5 (5)	9 (2)	2 (2)	16 (9)
Daily personal care (toileting/hygiene/dressing)	5	2	1	8
Daily help with ambulation (in/out of bed or chair)	3	1	2	6
Cleaning and/or laundry	3	0	2	5
Safety alarm	6	8	5	19
Support group	6	5	0	11
Regular respite care	3	6	0	9
Adult day care	2	5	1	8
Home nursing	2	5	1	8

**Table 5.** Contextual characteristics (modified version from paper V)

Contextual characteristics	Women (n=23)	Men (n=9)	Total (N=32)
<b>Place of living<sup>1</sup></b>			
Lives in rural area	3	3	6
Lives in urban area	20	6	26
Live in apartment (excluding SA/ALF <sup>2</sup> )			9
Lives in some type of SA/ALF <sup>2</sup>			6 spouses,
Have been granted home adaptations from the municipality			14 spouses, 2 mothers
<b>Distances to places of importance</b>			
Municipality centre > 5 km	3	3	6
Closest population centre (i.e. health care, pharmacy) < 1 km (Mean/range)	8	2	10 (M=3, R=0-20 km)
Closest grocery shop < 1 km (Mean/range)	9	3	12 (M=2, R=0-15 km)
<b>Nature</b>			
Close by < 300 m	23	9	32
Multiple caregivers who did not have time for recreation in nature	2	0	2
Do not use nature due to other reasons <sup>3</sup>	3	0	3
<b>Regularly use place for socializing (Mean/range)</b>	13	6	19 (M=7, R=0-60 km)
<b>Caregiver's capability to transport her-/himself and the carerecipient</b>			
Has a driver's license and can drive a car	13	8	21
Has been granted own transportation service	2	0	2
The Carerecipient is granted an accompanying person	11	7	18
Have close access to public transportations (mainly for caregivers' own transports)	17	6	23
Can transport her-/himself at times that suits her/him	22	9	31 <sup>4</sup>

<sup>1</sup> Two mothers resided in the same type of housing and neighborhood as their daughters, four resided in urban apartments.

<sup>2</sup> Senior Accommodation (SA) or Assisted Living Facility (ALF).

<sup>3</sup> Two women were too disabled themselves to venture into their gardens, one daughter was not interested.

<sup>4</sup> One wife had difficulties. She was granted transportation in her own accord, but found it expensive. Her husband drove an adapted car, which provided transportation when he was able to do it.

## Data collection

Data was collected for the entire study through one face to face interview with each participant during 2006 (Figure 2). Twenty caregivers were interviewed in their own homes (one in her mother's home next door), 12 at the municipal hall. The interviews lasted 1.5-3.5 hours (Mean = 2 hours, recorded data) regardless of location. A higher proportion of the men chose the municipal hall as location and only one man had his carerecipient present in an adjacent room in his home, compared to six wives and one daughter. There were no other obvious differences between the choice of location and caregiver or carerecipient characteristics, except that the mothers' whereabouts were usually not mentioned. One caregiver from each location opted to have extra formal support, and one interview from each location was prematurely terminated (I). These

caregivers completed the questionnaires alone and mailed them to the investigator the next day. One recording failed, but the questionnaire was completed and field-notes and a summary of unrecorded data was compiled the same day.

To collect data, an interview package was used and the interviews were recorded throughout. The interview package consisted of six phases and was designed to assemble different types of complementary data that would make it possible to unravel SRRs/GRRs and SRDs/GRDs in diversifying fields associated with the caregivers' situations. The interview phases and their intended function during data collection are presented in Table 6.

**Table 6.** The phases of the interview (modified version from paper III)

Interview phase <sup>1</sup>	Function during data collection
<b>Introduction (I)</b>	A phase to get acquainted, provide opportunity for questions and to ensure that the ethical information had been understood before the caregiver signed the informed consent document.
<b>Demographic Salutory Questionnaire, DSQ (I, II)</b>	Designed to assemble demographic and contextual data that may influence availability and usability of GRRs. Tested for face-validity and found valid after minor semantic alterations in a caregivers' support-group. Also used to acquire a 'contextual awareness' regarding each caregiver's specific context.
<b>Open-ended questions, OEQ (I, II)</b>	Salutogenically designed questions to inspire caregivers to elaborate on positive aspects in their situation in ways that made sense in their specific context, and to enable them to explain why these positive aspects were sometimes impossible to acquire.
<b>Caregiver Assessment Indices, CADI-CASI-CAMI (183, 184, 186)</b>	Originally designed to assess caregivers' levels of satisfaction (CASI), difficulties (CADI) and managing strategies (CAMI). In the study, used as structured questions to enable caregivers to provide reflections regarding their satisfaction, difficulties and managing aspects.
<b>Orientation to Life Questionnaire, SOC 29 (11, 187, 188)</b>	The original questionnaire developed to measure the SOC. It was used as 29 structured questions linked to the SOC-dimensions comprehensibility, manageability, meaningfulness and intended to trigger caregivers to evolve in descriptions associated with these dimensions in their particular contexts.
<b>Closure (I)</b>	A phase used to provide time to reflect upon the interview, add comments and pose questions. It was also used to assemble data regarding caregivers' experiences from participating in an interview using this approach and their suggestions regarding methodological improvements.

<sup>1</sup>For references within parenthesis – see reference list.

## **Interviews**

The interviews were conducted as a conversation focusing on salutogenic aspects; salutogenic interviewing (166-168, 182). Each interview was individualized and interactive as probing questions were based on what caregivers brought into the conversation. The salutogenic foci shed light on caregiver SRRs/GRRs and SRDs/GRDs through questions regarding *why*, *how*, and *why not* when they described challenges they encountered (I-V). *Whys* and *hows* denote that focus of attention was their reasoning regarding why something was positively described and their intentions or motives for managing a challenge in a particular manner (i.e. 'positive' life experiences indicating usable SRRs/GRRs). *Why not*s denote that focus was their reasoning regarding why they were unable to resolve a challenge to derive their desired outcome (i.e. 'negative' life experiences induced by the presence of SRDs/GRDs).

Two phases of the interview (Table 6) contained questions specifically designed for this study; the Demographic Salutory Questionnaire, DSQ, and Open-ended Questions, OEQ (Supplement to paper II). DSQ was extensive and used early in the interview to enable the investigator to derive a 'contextual awareness' of each participant's particular context, which facilitated probing further into the interview. Two standardized, validated questionnaires were used as structured questions; the Swedish version of The Caregiver Assessment Indices (CADI-CASI-CAMI) (183), originally designed to assess caregiver needs, now it has been validated for use in research (184-186). Due to the salutogenic approach, the order of the presentation of CASI and CADI during the interviews was changed to CASI-CADI-CAMI. The indices focus on aspects associated with caregivers' satisfaction (CASI), difficulties (CADI) and managing (CAMI).

The *Orientation to Life Questionnaire, SOC-29*, is an instrument developed to measure Sense of Coherence as a global orientation to life through its dimensions comprehensibility, manageability and meaningfulness (11). It has been used in a variety of settings and has been found to be a reliable and valid measurement of how people manage stressful situations and stay well (28, 176, 187), a Swedish version was used (188). Since the entire interview was recorded, probing questions during ratings derived qualitative data associated with the individual caregiver's satisfaction, difficulties and how they managed (direct answers to questions). Caregivers' reasoning during ratings, when a question triggered them to evolve into descriptions of other aspects or make additions to something previously discussed, derived extensive amounts of qualitative data. Each interview was therefore considered one data unit during the analysis, regardless of which phase the qualitative data originated from (I).

## **Field-notes**

In conjunction with each interview, field-notes were made regarding aspects that were assumed to have potential value during the analysis (i.e. instant impressions regarding the environment and particular context, how the interview had evolved, caregiver's mood etc). These notes were considered essential since the interviews were extensive and it would be impossible to transcribe each one before conducting the next. To retain information when it was fresh in memory, each interview was listened through



the same day, or within a few days after it had been conducted and reflections during this process were added to the field-notes. Together with some DSQ-data, these notes were transcribed as each interview's 'naïve story', a sort of qualitative, subjective 'base-line'. These naïve stories were used to support the investigator's memory when searching for particular data, to trig the development of memos and to indicate the reasonableness in emerging findings during coding at an individual level.

## Data analysis

All data was analyzed during the same period of time, in this thesis labelled 'data analysis', which also derived a synthesis of findings. The four different parts in this synthesis are presented in paper II-V and the synthesis in 'Findings' in this thesis. Before this analysis begun, data was structured to enable movements between the different kinds of data during the analysis (I). Quantitative raw data was coded using a code-manual and assembled in a Microsoft Excel-file<sup>®</sup>. This code-manual was construed in a manner which made distinguishing between variables optimal (i.e. numbers, letters and colors). It was primarily used as an analytical tool to visualize quantitative data as a base for the development of memos when elucidating qualitative data and to develop tables, both for the analysis and later to describe the population and context in the papers.

DSQ-variables were entered before the qualitative analysis was conducted (143 per caregiver), and variables from CADI-CASI-CAMI (97 per caregiver) and SOC-29 (29 per caregiver), were entered afterwards in order to minimize premature conclusions, mainly due to caregivers' SOC-scores. Due to discrepancies between quantitative variables from CADI-CASI-CAMI and qualitative data during ratings (I), these variables were only used descriptively when following a few memos (e.g. which statements rendered highest/lowest total sums, what did qualitative data in these individual statements provide by way of explanation et cetera). Qualitative, raw data encompassed naïve stories (35 pages) and transcribed text from all phases of the interview (Table 6) excluding 'Introduction', data from one interview and the DSQ-phases from the first four interviews (61 hours and 918 pages in total).

Memos (Figure 3, and paper I) guided the analysis (189). *Methodological* memos were concerned with the research-process, induced reflexivity and 'guarded' against biases due to preconceptions (178, 190). An example of a methodological memo: 'Compare X with Y to refine subtheme Z' or 'Am I seeing X in data as a researcher or as a homecare nurse?' *Analytical* memos were hunches and ideas directly related to the process of unravelling SRRs/GRRs and SRDs/GRDs. These memos could be derived when reading text (qualitative), filtering the Excel-file (quantitative) or have a mixed origin.

Following an analytical memo was a journey along a continuum of data enabling quantitative and qualitative data to interact to derive a deeper understanding regarding the caregivers' life experiences, their tension management and the involved SRRs/GRRs and SRDs/GRDs. Memos found incongruent with data were abandoned or new memos were generated.



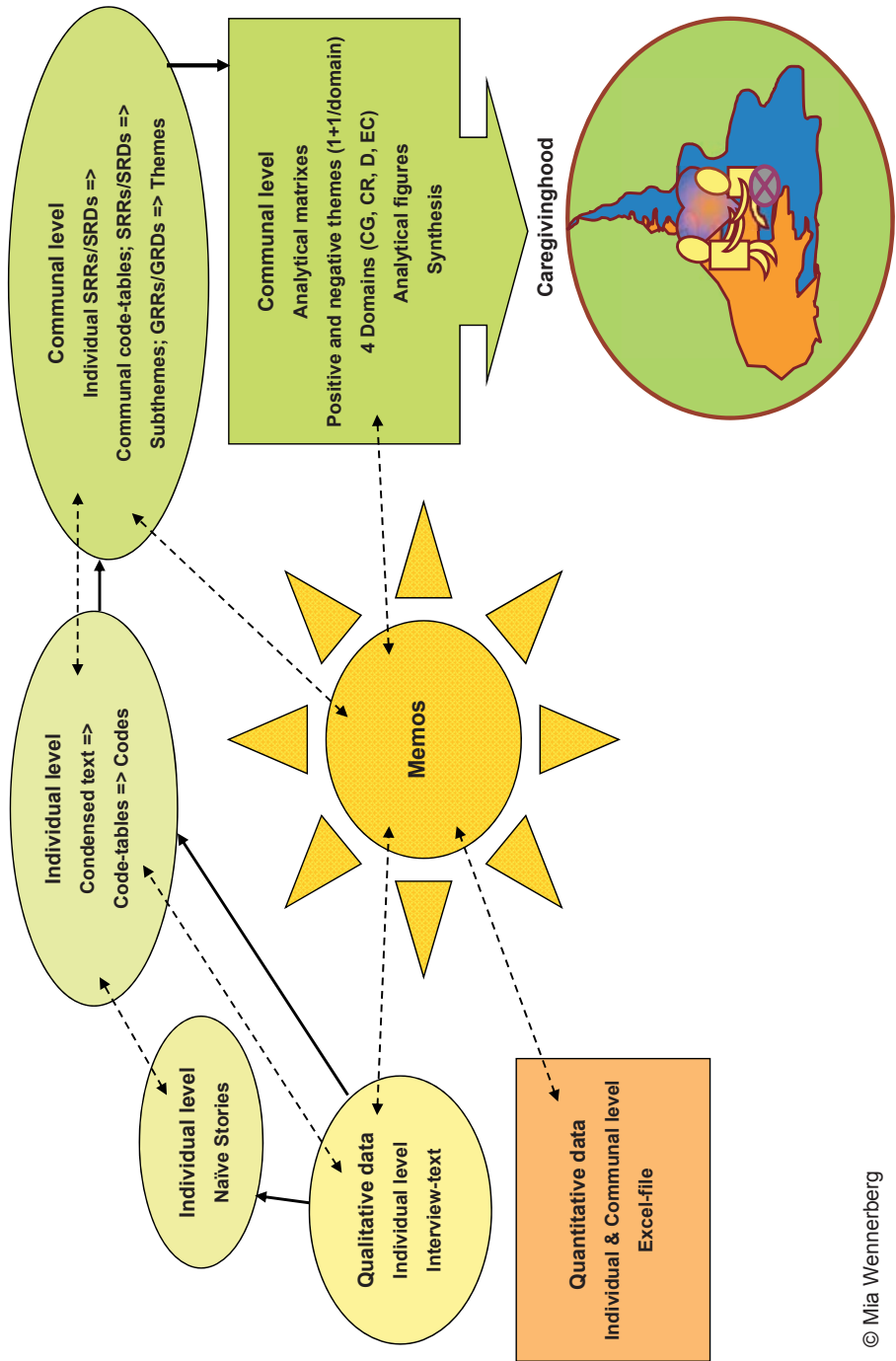


Figure 4. The process of data analysis.

The analysis was theory-driven, mainly qualitative and conducted in both an inductive and deductive manner (Figure 3 and 4). Even if all caregivers provided care in the same outer context (the municipality), their own specific circumstances and the options these provided determined their tension management. According to the theoretical framework, different types of tension management may be used by different persons to resolve the same type of challenge, or the same type to resolve different types of challenges, depending on the individual circumstances and context. Due to such contextually related differences, within-case analysis (177) was utilized to inductively extract codes (qualitative example, Figure 3) referring to positive and managing aspects, the *how* and *why*, in each caregiver's descriptions of successful tension management, and codes referring to negative aspects, *why not*s, involved in unsuccessful tension management. These codes were compared, merged and transferred to interview-specific code tables using colors to distinguish them from each other. The SRRs emerged as reasons to why a caregiver resolved certain challenges in her/his particular manner to derive 'positive' life experiences. SRDs, as reasons to why they could, or would, not use available SRRs/GRRs, frequently due to concurrent aspects within their specific context during certain circumstances, thereby SRDs derived 'negative' life experiences (Figure 4).

In a second analytical process, deduction was utilized across cases (10,11,177) to identify characteristics uniting SSRs and SRDs on a communal level. During this process, the Excel-file<sup>®</sup> (example, Figure 3), was used to find individual caregivers when following memos and comparing SRRs/SRDs across cases. This process was guided by the theoretical definition of GRRs (10 p. 103) and theoretical knowledge regarding the function of GRDs (presented as a 'serviceable GRD-definition' in paper III). Without deduction at this stage, it would have been impossible to reach the level of abstractions where the individual context did not matter and the individualized SRRs and SRDs could be united as GRRs and GRDs as '*contextually grounded generalizable findings*' (177 p. 871) representative for the group of caregivers (Figure 4).

The analytical process was a journey from structured raw quantitative and qualitative data, through the two analytical processes guided by memos to the contextually grounded generalizable synthesis of findings, *Caregivinghood*, which emerged as a communal context, encompassing four domains of GRRs and GRDs (including SRRs/SRDs) based on their origin. Two themes in each domain united the essences of experiencing the domain specific GRRs and GRDs. The domains were; the Caregiver, CG- (II, III); Carerecipient, CR- (II, III); Dyad, D- (IV) and Environmental/Contextual, EC- (V) domains (Figure 4). GRRs and GRDs are presented in the papers together with their SRRs/SRDs which are visualized in citations from the interviews to describe the variation encompassed in each GRR/GRD (II-V). The synthesis of findings is presented in 'Findings' in this thesis.

## Ethics

Approval to conduct the study was obtained from the municipality's political council and local officials. According to the Ethical Research Committee of the Faculty of Medicine at the University of Gothenburg, Sweden, permission to conduct the study was not required for this type of study design at that time (2004/2005).

Ethical guidelines from the Swedish Council for Research in Humanities and Social Sciences HSFR (181) were followed.

All participants were informed orally and in writing about the background and aim of the study that it was a doctoral project and that the investigator (author of this thesis) was a homecare nurse without professional ties to the municipality. It was emphasized that their participation was voluntary and that they had the right to decline participation at any time without explanation and contact information they could use for this purpose was provided to the participants. The caregivers were also informed that the care managers inviting them would not know whether they had participated or not, thereby it would be unlikely that their participation in any way would affect their future contacts with professionals representing the municipality. Each participant was assured confidentiality and informed that the interview material would be handled sensitively. Procedures regarding the recordings and how the results from the study should be published were explained in detail.

Practical arrangements were made according to caregivers' wishes (location, time, need of formal support during the interview et cetera.) since the caregivers' situations required a high degree of flexibility. During the introduction, when they signed informed consent, and the closure phase (Table 6) any questions the caregivers had regarding ethical issues and the study were discussed and they were provided with contact information to the local carers' consultant who was available if the interview had aroused questions they would like to discuss. The investigator's (author's) homecare experience was assumed to be enough to manage difficulties, such as affect, during the interviews (I).

## FINDINGS

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The study was designed to identify and describe what SRRs/GRRs and SRDs/GRDs may consist of in a group of caregivers to older adults. These concepts were unravelled as individual, communal, circumstantial or contextual characteristics evoked or enhanced by caregiving:

- SRRs/GRRs (II, IV-V) were described as emotions, capabilities and circumstances that seemed empowering, enabling and facilitating; the answers to *why* and *how* during the data analysis. To be able to use and re-use them, enhanced a caregiver's capability to resolve challenges; they could obtain a 'fit' between available SRRs/GRRs and a desired outcome. Thereby SRRs/GRRs, derived 'positive' life experiences which, theoretically induce movements towards the health end on the health continuum.
- SRDs/GRDs (III-V) were described as emotions, shortcomings and circumstances impeding, hampering and obstructing the use of available SRRs/GRRs, or indicated lack of the appropriate ones, when facing challenges; the answers to *why not* during the analysis. Through this function, they hindered directly, or indirectly through anticipated adverse consequences, successful tension management and induced a 'lack of fit' between available SRRs/GRRs and what was required to obtain a desired outcome. Thereby SRDs/GRDs provided 'negative' life experiences which theoretically induce movements towards the dis-ease end on the health continuum.
- SRRs/SRDs were individualized and determined the options a caregiver had to resolve challenges during specific, individual circumstances.
- GRRs/GRDs were generalized in two ways; 1) Each GRR and GRD encompassed the entire amount of an individual caregiver's SRRs or SRDs associated with that particular GRR or GRD (e.g. CG-GRRs encompassed all SRRs stemming from a caregiver her/himself, the CG-domain, but she/he could only use them during specific circumstances). 2) Each GRR and GRD also encompassed the entire group of caregivers' SRRs or SRDs associated with that particular GRR or GRD.

### Caregivinghood

Based on their origins, GRRs and GRDs (including SRRs and SRDs) were found to originate from four domains; the Caregiver, CG- (II, III), Carerecipient, CR-(II, III), Dyad, D- (IV) and Environmental/Contextual, EC- (V) domains. In each of these domains, two themes united the essences of having access to the encompassed GRRs or experiencing the GRDs. Together these domains made up the contextually grounded generalized synthesis of findings describing a phase of life, *Caregivinghood*.

In Figure 5, at an individual level, the caregiver (CG) and carerecipient (CR) are situated in their respective *life spaces* containing their individual SRRs and SRDs (CG- and CR-domain). They are sharing their dyad specific SRRs and SRDs encompassed in their dyadic life space (D-domain). These life spaces are situated in an environment/context (EC-domain) encompassing SRRs/SRDs specifically related to the unique situation each caregiver, carerecipient and dyad have. The EC-domain also encompasses GRRs/GRDs shared by the group of caregivers, carerecipients and dyads (e.g. policies, welfare system, geographical prerequisites). The figure shows that the life space borders are fluctuating vis-à-vis each other and that they progressively shrink towards a point when Caregivinghood ends (III). The synthesis of the themes in each domain derived a core-theme uniting the caregivers' experiences during this phase of life based on their access to usable SRRs/GRRs and the presence of SRDs/GRDs; *Being situated in the duality of Caregivinghood*.

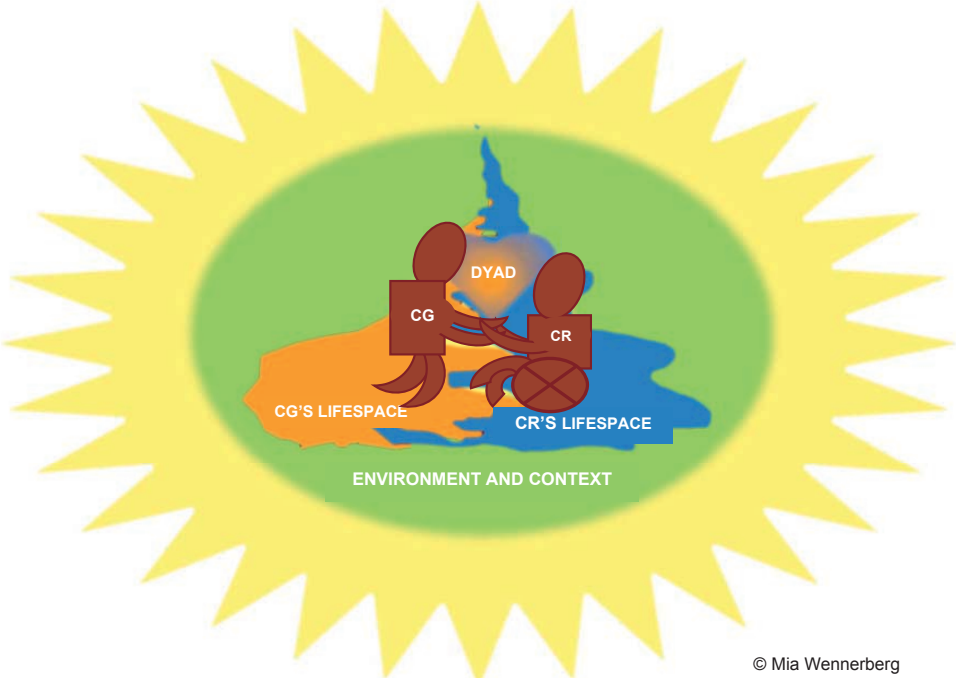


Figure 5. Being situated in the duality of Caregivinghood.

### Being situated in the duality of Caregivinghood<sup>3</sup>

In order to make the finding-section in this thesis comprehensible, manageable and meaningful, the presentation will start at the end with the contextually grounded generalizable synthesis of findings labeled *Caregivinghood*. This label originates from, mainly female, caregivers' comparisons between their current challenges and those experienced when bringing up their children to adulthood, their parenthood years:

*...a child will grow up, they'll be able to manage by themselves, but a person you're caring for who's sick... he'll never be better... not in two years [as a child usually is]...a kid you may hoist onto your arm and take with you but.....[not a husband] (CG, 7)*

Parenthood and Caregivinghood may both be viewed as phases of life 'governed' by internal and external characteristics (SRRs/GRRs, SRDs/GRDs), influencing the options individuals have when facing challenges and conducting their lives. During both of these phases, an individual's life spaces are affected by responsibilities for someone incapable to manage on her/his own. Each individual's internal characteristics influence how they experience their situation, but as a group during a particular phase of life, they are affected in the same manner by a range of characteristics. For example; both phases encompass queuing systems for services enabling caregivers to use their specific resources (SRRs) to do other things than to provide care. How accessible the environment is for someone using wheels to ambulate, have the same effect on caregivers' and dyads' ability to use SRRs during both phases. The dyadic process of caregiving is dependent on the ability to communicate (verbally/non-verbally); good communication (SRR) facilitates caregiving, whilst difficulties to communicate (SRDs) may obliterate the use of SRRs and make dyads malfunctioning. Such effects are usually temporary during adolescence, whilst permanent and accumulating when an older adult is proceeding into dementia.

Contrary to parenthood, wherein the caregiver's life space shrinks abruptly at the start due to loss of usable SRRs/GRRs, which the caregiver successively regains as the child's independence increases, the situation during Caregivinghood is the reverse. When entering into Caregivinghood the life spaces are usually fairly equal, at least the size the dyad has agreed upon. During the journey through Caregivinghood, the amount of SRDs/GRDs accumulate due to the carerecipient's increasing dependency (CR-SRDs, III). The consequence is that a caregiver's amount of usable SRRs/GRRs decrease since their life space is successively imbued by the carerecipient's (also shrinking), and the dyadic life space starts to disintegrate, at least vis-à-vis their previous environment/context. Towards the end of Caregivinghood, the caregiver is left with few usable SRRs/GRRs and Caregivinghood ends.

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<sup>3</sup>When using 'GRRs' or 'GRDs' in the following section, they include the encompassed SRRs/SRDs on group level. If 'SRR' or 'SRD' referring to the individual level is used, they are attached to the domain they originate from (table 7). For example; the D-GRR 'Enjoying togetherness' encompass a range of D-SRRs, but all serve the specific purpose to enable dyads to enjoy togetherness. It is not possible to present the individualized variation of SRRs/SRDs on group level, only to provide some examples.



Parenthood, legally ends when a child come of age, whilst the length of the journey through Caregivinghood differs considerably between caregivers and have no set limit regarding its length. Figure 5, schematically shows the most frequent type of journey for groups of caregivers like the one participating in this study. In Table 7, the ‘positive’ themes, looked at as a whole, show the ‘optimal scenario’ when having access to GRRs to keep the life space borders at bay. The ‘negative’ themes show the ‘worst case scenario’, when the capability to use available SRRs/GRRs is almost/completely lost due to GRDs and the life spaces have almost/completely disintegrated. To be able to make a comprehensive description of GRRs and GRDs, they are presented as ‘optimal’ and ‘worst case’ scenarios in each domain; GRRs first, then GRDs. More realistic descriptions showing the individual variation and the duality at the individual level, are presented as citations from the interviews (SRRs/SRDs) in the papers (II-IV).

### ***SRRs/GRRs – Resources keeping life space borders at bay***

The theme *Being someone significant in my own eyes* unites the essence of being able to use SRRs stemming from oneself to find a ‘fit’ when facing challenges (Table 7 and paper II). The four GRRs and the theme indicates that caregivers may have what Antonovsky described as a ‘*pervasive, enduring though dynamic feeling of confidence*’ (II, p. 610), an inner trust in oneself and one’s capability, which may be viewed as part of an orientation to life reflecting ‘*ego-identity*’ stated as essential for the development of a strong SOC (II). Findings support this notion since caregivers’ descriptions indicated that their inner trust of ‘being someone significant’ was merely temporarily diminished until they found the appropriate SRRs to comprehend, manage and resolve their challenges (i.e. I have, or will eventually find, a way to resolve this challenge or prevent it from reoccurring). SRRs used to acquire this inner trust and find meaning in what she/he was doing, were such as trusting one’s capability and knowledge regarding how to perform caregiving tasks. These caregivers had learned through ‘trial and error’, usually during a long time of informal or professional caregiving (Table 2).

‘Expert-competence’ regarding the carerecipient, was a SRR encompassed in the GRR *feeling capable and competent*, which enabled caregivers to facilitate so that the carerecipient could use her/his own remaining SRRs, and also to assess when she/he needed assistance or could try themselves without too many adversary effects. The GRR *harboring positive emotions* indicated SRRs enabling the caregiver to view most things out of a positive perspective, having the ability to internalize positive feelings and to use humor to manage. The GRR *being able to create breathing spaces* indicated *the conviction* of being able to create ‘breaks’ from caregiving when they felt the need, such as leave a situation for a short while to regain her/his composure instead of letting it evolve into chaos. These are examples of how caregivers used SRRs stemming from themselves to acquire a ‘fit’ when facing challenges.

The theme *Being ‘blessed’ with a cooperative co-worker* unites the essence of GRRs originating from the carerecipient (Table 7 and paper II). Even if a caregiver frequently resolved challenges through the use of solely their own SRRs, the most positive life experiences stemmed from descriptions of when a combination of their own and their carerecipient’s SRRs had been used; a ‘fit’ acquired through cooperation. The three GRRs encompass CR-SRRs that function as GRRs for the caregiver since

Table 7. Domains, themes, GRRs and GRDs in Caregivinghood

Domain	Themes and GRRs	Themes and GRDs
Paper II & III: Caregiver (CG)	<p><b>Theme</b> Being someone significant in my own eyes</p> <p><b>GRRs</b> Feeling capable and competent Harboring positive emotions Being able to create breathing spaces Being able to find meaning</p>	<p><b>Theme</b> Experiencing personal deficiencies</p> <p><b>GRDs</b> Lacking capability Harboring negative emotions Lacking solitude Lacking meaning</p>
Paper II & III: Carerecipient (CR)	<p><b>Theme</b> Being 'blessed' with a cooperative co-worker</p> <p><b>GRRs</b> Possesses an easy-going, good-natured personality Possesses the impulsion towards improvement Is accommodating, docile and tractable</p>	<p><b>Theme</b> Struggling with an uncooperative co-worker</p> <p><b>GRDs</b> Lacking in physical capability Lacking in communicative skills and judgement</p>
Paper IV: Dyad (D)	<p><b>Theme</b> Living in fellowship in a well-functioning dyad</p> <p><b>GRRs</b> Living in reciprocity Living in affinity Enjoying togetherness</p>	<p><b>Theme</b> Struggling in a malfunctioning dyad</p> <p><b>GRDs</b> Lacking twosomeness Living in unpredictability Being overloaded Being bullied and counteracted Becoming a container for negative emotions</p>
Paper V: Environmental/Contextual (EC)	<p><b>Theme</b> Being in empowering surroundings</p> <p><b>GRRs</b> Working in enabling surroundings Caregiving in relative ease Having a supportive support system</p>	<p><b>Theme</b> Struggling in impeding surroundings</p> <p><b>GRDs</b> Working in hampering surroundings Being in a presumptuous context Being in the hands of an unsupportive support system</p>

they facilitate and ensure the carerecipient's cooperation when resolving challenges. A prerequisite for this cooperation was that caregivers knew how, and to what extent, their carerecipients could contribute and *harbored the conviction* that they would try.

The encompassed GRRs indicate that the carerecipient possessed SRRs (e.g. personality traits, capabilities, motivation), that made them easy-going, good-natured and fun to be with and that they had managed to preserve these traits even into dependency (GRR, *possesses an easy-going, good-natured personality*). Some carerecipients possessed their own inner motivation, an impulsion, to make the best of the situation. They strove to preserve their SRR-usage (e.g. persuaded the caregiver to let them take a walk alone) and did not command constant attendance (GRR, *possesses the impulsion towards improvement*), which enabled their caregivers to use available SRRs to enhance their own wellbeing (e.g. Nordic Walking, participate in an evening class). Some carerecipients, too impaired to be able to cooperate actively, cooperated through not demanding too much, and complying with their caregiver's suggestions (GRR, *is accommodating, docile and tractable*). SRRs encompassed in the CR-GRRs enabled caregivers to count on their carerecipients to contribute as best they could to share the workload, which facilitated the dyad's journey through Caregivinghood.

The theme *Living in fellowship in a well-functioning dyad* unites the essences of having access to SRRs/GRRs emanating from the caregiver-carerecipient as a dyad (Table 6 and paper IV). Most *reasons* and *prerequisites* for why certain characteristics became SRRs/GRRs in this domain, are encompassed in the other domains, whilst the *dyadic consequences* of having access to them, determined D-GRRs. The three GRRs originate from personal characteristics (e.g. personality traits, values, preferences) which over the years had evolved as shared, dyad-specific characteristics (D-SRRs). In dyads living in fellowship consisting of spouses, the edges of each one's personality had been grinded to fit the partner's during decades of being together (Table 2), resulting in a shared frame of reference regarding how things should be within their relationships and vis-à-vis others. The daughters were brought up sharing such a frame of reference with their mothers and could recall it and adapt to their mother's preferences when providing care (IV).

During Caregivinghood, the caregiver is usually, and progressively, the most significant actor due to an increase in the carerecipient's deficiencies. Even so, in dyads living in fellowship, the GRR *living in reciprocity* indicates the 'give and take' in a relationship and caregivers who had access to this GRR usually provided care to carerecipients who strove to contribute as best they could (e.g. actively or passively). The emotional and existential GRR *living in affinity* 'glued' the two parts in the dyad together. For daughters, and caregivers who received little feed-back from severely impaired carerecipients, their dyadic affinity seemed to serve as a motivational component that gave meaning to providing care; they were able to 'give back' to the one who had provided for them before. Some caregivers to cognitively impaired carerecipients seemed convinced that the mutual affinity was still there and used this SRR and their dyad's frame of reference 'to do the right thing' when resolving dyadic challenges on their own. This was described as comforting and seemed to derive a reciprocity of sorts. Dyads living in fellowship, continued to enjoy the togetherness

they had shared for a long time, even if their activities were adapted to their current circumstances and dependent on which SRRs in the other domains they could still use (GRR *enjoying togetherness*). Dyads that had access to D-SRRs, could cooperate and used their specific dyadic tension management to derive, their agreed upon, desired outcomes (a ‘fit’ acquired through cooperation). This manner to resolve challenges preserved their dyad-functioning for as long as they had access to, for them, essential SRRs in all domains.

The theme *Being in empowering surroundings* unites the essence of being able to use SRRs/GRRs originating from the environment and context in which caregiving takes place to acquire a ‘fit’ between the caregiver’s, carerecipient’s and dyad’s desired outcome (Table 7 and paper V). Caregiving research has shown that to provide informal care is hard work and caregivers may thereby be considered informal care ‘workers’ providing homecare, just as formal care workers do. However, caregivers are not usually regarded as ‘workers’ and their ‘workplaces’ generally not designed and equipped to facilitate their work or prevent injuries, unless formal care workers are involved since their work is governed by regulations. Neither the caregiver, nor the dyad can change much in their environment/context themselves, unless they change the location of their workplace. Some dyads did this, due to seasonal changes, to enhance their access to SRRs/GRRs. Other caregivers, had done so permanently. These caregivers had regained access to SRRs their previous premises had made unusable, acquired access to new usable SRRs, and their shrunken life spaces could evolve. The caregiver’s ‘workplace’ could also be their home and several caregivers either lived in adapted facilities, or had obtained home adaptations and assistive devices from the municipality based on their carerecipients’ needs, occasionally even based on what they needed themselves to provide care (Table 5).

Experiencing that the workplace was enabling indicated that it was dispositioned and equipped to facilitate cooperation and that the location enabled caregivers and carerecipients to leave it, alone or together, to use available SRRs/GRRs. EC-SRRs, such as accessibility and infrastructure, determined which available SRRs/GRRs in the other domains these caregiver and dyad could use, since they frequently determined whether or not a ‘fit’ could be acquired (Table 2-5 and papers II-V). Some caregivers described being in familiar surroundings as an EC-SRR, crucial for their ability to provide care and use SRRs. Regarding caregivers mainly as access to informal support, and for carerecipients’ it was an essential SRR enabling them to use of what remained of their own CR-SRRs. Three of these carerecipients suffered from several physical diseases whereof two in combination with blindness, and another two were severely affected by dementia (CR-SRDs).

The contextually dependent EC-GRR *caregiving in relative ease*, unites SRRs related to the specific reasons for caregiving, development of the situation in relation to time and compared to other caregivers’ situations or how caregiving was described by non-caregivers (e.g. media). The GRR per se, said nothing about how burdensome the situation was at present, only that it encompassed SRRs that, out of the caregiver’s perspective, made it easier than previously and compared to how other caregivers described caregiving and Caregivinghood.

None of the caregivers ‘worked’ alone, they all had access to some kind of informal or formal emotional and practical support (Table 4 and paper V). Even so, the variation was extensive regarding who the provider was, the amount and frequency of support, its appropriateness and how content caregivers were with what they received. Support was considered an EC-GRR if it was enabling, facilitating and useful when facing challenges. The GRR *having a supportive support system* indicates that the caregivers had access to the ‘right’ type of support; a support that could ‘bridge the lack of fit’ between available, but not usable, SRRs. Such support enabled the caregiver/dyad to find a ‘fit’ between SRRs and a desired outcome, could enhance cooperation and preserve dyad-functioning, depending on the type of support caregivers were referring to.

### **SRDs/GRDs – Deficits inducing life space shrinkages**

The theme *Experiencing personal deficiencies* (Table 7 and paper III) unites the essence of experiencing SRDs stemming from the caregiver her-/himself. Due to the presence of these SRDs, the caregiver could not obtain a ‘fit’ between available SRRs and a desired outcome. They described this unsuccessful tension management as failing in their ‘duties’ due to personal characteristics, such as being too weak, too exhausted or lacking knowledge which reduced their motivation even to try to acquire a ‘fit’ when facing challenges (GRD *lacking capability*). To frequently experience a range of negative emotions, or the prospect of experiencing them, made caregivers refrain from trying to use available SRRs, expressed in terms of ‘it is not worthwhile trying’ (GRD *harboring negative emotions*).

The GRD *lacking solitude* was derived from descriptions of missing the ‘content’ they used to fill their time in solitude with, which induced consequences like feeling entrapped, restrained and regulated. They could not, or would not, use available SRRs to recuperate, take care of their own health or to nurture social relationships, since such activities required solitude, could induce negative emotions (e.g. guilt, carerecipient’s anger) or preparations made the caregiver too exhausted. SRDs encompassed in the GRD *lacking meaning* ranged from the pointlessness most caregivers experienced occasionally when they tried to use certain SRRs, to a state of meaninglessness that permeated some situations.

Caregivers experiencing SRDs encompassed in most of the CG-GRDs tended to view everything out of a negative perspective and seemed to consider caregiving an endless, lonely and meaningless struggle they never could create enough time to recuperate from, regardless of the underlying reasons (SRDs). Whether this way of viewing their present situation was due to an orientation to life indicating a weak SOC and few usable SRRs already when entering into Caregivinghood, or if it was an effect of having provided care during a long time and thus acquired an accumulation of SRDs, was not possible to discern. A few caregivers describing their situation in these terms were obviously, based on homecare experience, close to the ‘breaking-point’ where Caregivinghood ends; they had few usable SRRs/GRRs left and most life spaces had disintegrated (III).

The theme *Struggling with an uncooperative co-worker* (Table 7 and paper III) conveys the impression of caregivers perceiving themselves as failing in their ‘duties’ due to carerecipient characteristics they were unable to change (e.g. personality traits, type of impairment). Most carerecipients were not uncooperative on purpose, but their SRDs made them uncooperative out of a caregiver perspective since they could not count on them as co-workers when facing challenges, thereby the experience of ‘struggling’. The SRDs encompassed in the GRD *lacking in physical capability*, hampered the use of available SRRs requiring ambulatory capability, certain movements or other physical functions (e.g. being continent, being able to see), thereby caregivers’ options when facing certain challenges decreased. The effect of the deficit was mainly physical strain for the struggling caregiver, but it could also lead to dyad-isolation. Some lack of capability, such as being incontinent or suffering from sleeplessness (SRDs), had both physical, psychological and social effects. If both caregiver and carerecipient lacked in physical capability, the negative impact on caregiver health increased considerably through accumulation.

The most devastating CR-GRD was *lacking in communicative skills and judgement* which induced a range of SRDs obliterating the use of SRRs requiring that the caregiver could communicate intentions or instructions. These SRDs were united in one GRD due to the effects they had on caregivers’ tension management, not the underlying reasons which caregivers could not always discriminate between (e.g. deafness vs. cognitive impairment vs. psychiatric disorder). Regardless of the reason the GRD, directly or indirectly, induced a range of negative effects and emotions. The encompassed SRDs could also turn CR-SRRs (e.g. wanting to ‘help’) into SRDs if the carerecipient used them in an inappropriate or dangerous manner, then it became a challenge the caregiver had to find usable SRRs to prevent. Caregivers knew what was required when facing challenges, but could not communicate their intentions, nor make their carerecipients understand or comply. Thereby this CR-GRD threatened the caregiver’s health and the dyad’s functioning in multiple ways.

The theme *Struggling in a malfunctioning dyad* unites essences of experiencing dyadic SRDs/GRDs (Table 7 and paper IV), which may be viewed as effects of, or aspects due to, being in a malfunctioning dyad. How functional a dyad was during Caregivinghood, seemed related to its prior dyadic history when entering into Caregivinghood and the type of impairment/-s inducing the care need (Table 3). A few caregivers had spent their entire period as spouses in what seemed to be malfunctioning dyads, wherein both parties had lived separate lives. These dyadic life spaces seemed almost non-existent already when entering into Caregivinghood, since the two parts in the dyad, had rarely cooperated towards a mutually desired outcome and they had assembled a range of SRDs in their dyadic ‘backpack’. The effects of these SRDs increased when one part became dependent. For example, when a need to have control evolved to the GRD *being bullied and counteracted* when the carerecipient lost her/his judgement, or a sparse dyadic conversational manner became a complete lack of feed-back (D-SRD). In such dyads, most possibilities to cooperate and resolve challenges towards a mutually desired outcome were almost impossible since these dyads had not acquired a dyad-specific type of tension management.

When dyads wherein a fellowship had existed previously became malfunctioning, the lack of usable D-SRRs/GRRs brought utterly sorrow, especially if the carerecipient's communicative skills and judgement were affected. These caregivers struggled to maintain dyad-functioning without the essential assistance from their previous co-workers and companions who had lost most of her/his own SRRs. Their dyadic life space was permeated by the GRD *lacking twosomeness* and all of their life spaces were shrinking, how fast depended on the amount of SRDs they acquired and whether they had access to the 'right' type of support (EC-GRR). Not having acquired a specific dyadic tension management, or when it was not usable anymore due to SRDs, increased the caregiver's workload and induced a range of CG-SRDs (e.g. disappointment, exhaustion).

One reason why the dyad's specific type of tension management became unusable, permanently or in association with specific challenges, was due to traditional gender roles in this group of caregivers. Especially females, could become overloaded (GRD *being overloaded*) when they had to take over their partner's previous chores on top of their own, even if some females expressed pride regarding having mastered the new skills (CG-SRRs). However, such a mastering frequently required that they could access the 'know-how', which was sometimes impossible in malfunctioning dyads where there had been little interchange regarding chores (D-SRDs), or when the carerecipient lacked communicative skills (CR-SRD). Caregiving males and male carerecipients, including those possessing CR-SRRs that usually made them excessively cooperative, seemed to share the view that housework was not part of their 'dyad deal'. This point of view, became an SRD negatively affecting cooperation which could have eased the workload, mainly for female caregivers. Caregivers with extensive responsibilities on top of providing care in their dyads (e.g. multiple caregivers, working caregivers), became 'sandwiched' between different responsibilities which induced overload due to such as stress and dis-satisfaction with almost all of one's performances.

The unpredictable nature of the situation per se (D-GRD *living in unpredictability*) could also make a dyad malfunctioning. For example; some SRRs were usable during certain circumstances, not during others, which made it impossible to predict when available SRRs would be usable and thus obliterated the ability to plan ahead. General decline in both the caregiver's and carerecipient's health due to ageing (CG-, CR-SRDs) induced worries regarding the dyad's future in Caregivinghood. Regardless of the underlying reasons, caregivers in malfunctioning dyads struggled to maintain some dyad-functioning, even if they were usually left with total responsibility and half the knowledge regarding dyad-affairs. They were forced to act in certain ways, or prevented from acting in what they described as the optimal, proper way (e.g. had few usable SRRs/GRRs), leaving them in a state of existential loneliness in a situation wherein all life spaces were shrinking.

The theme *Struggling in impeding surroundings* unites the essences of experiencing environmental/contextual SRDs/GRDs hampering and obstructing, thereby counter-acting a caregiver's, carerecipient's or dyad's capability to acquire a 'fit' between

available SRRs/GRRs and a desired outcome (Table 7, paper V). *Working in hampering surroundings* due to material aspects, such as a workplace's disposition, equipment and/or location, could counteract each individual's use of their own available SRRs, and the dyad's capability to cooperate, which frequently increased the workload. For example; a 'lack of fit' between distance to the shop, mood of transportation (Table 5) and CR's loneliness capability (Table 3) obstructed caregivers' capability to do their own shopping (CG-SRR). Accessibility deficits (EC-SRDs) hampered carerecipients' capability and thwarted their motivation, to take a walk alone (CR-SRR). Lack of access to appropriate options for transportation, obliterated the dyads' abilities to pursue activities they enjoyed doing together (D-GRR). Experiencing EC-SRDs could, over time in this manner, make available SRRs (e.g. mobility, strength) or GRRs (e.g. enjoying togetherness) in other domains permanently unusable due to lack of use or practice.

The dyad was also situated in a context which sometimes was presumptuous regarding how the caregiver and carerecipient were supposed to be and act, as individuals and as a dyad, during this particular phase of life (GRD *being in presumptuous surroundings*). Especially for caregivers, SRDs encompassed in this GRD, increased their workload and induced a range of other negative effects. These SRDs were such as not being listened to or lack of empathy/ignorance regarding the effects different decisions, regulations and un-written rules associated with 'appropriate caregiver behaviour' had on their workload. These SRDs were mainly induced during contacts with professionals in different contexts.

When interacting with significant others the caregiver, or dyad, sometimes wanted to preserve the 'presumptions' these had regarding the situation and hid how challenging, difficult or problematic the situation was. This caregiver behaviour rendered consequences encompassed in the GRD *being in the hands of an unsupportive support system* (V), even if significant others were not unsupportive out of choice. Regardless of the underlying reasons, formal and informal support consequences deriving 'negative' life experiences, were described as not receiving the appropriate support to make available SRRs usable, or receiving the 'wrong' type. The 'wrong' type of support was not individualized and flexible enough to bridge the 'lack of fit' between available, but not usable, SRRs and a desired outcome. The providence of support (when, how) and aspects associated with using it (e.g. rules and regulations associated with formal support, or preferences regarding informal), sometimes induced more SRDs and challenges than the ones the support was supposed to diminish. It became the 'wrong' type and caregivers refrained from using it; it was useless or increased their workload.

### **The 'fit' and 'lack of fit' during Caregivinghood**

Previously in findings, the journey through Caregivinghood was described using the 'optimal' and 'worst case' scenario to acquire a comprehensive presentation of SRRs/GRRs, SRDs/GRDs and themes in each domain. SRRs and GRRs are per definition resources, whether they are usable, depends on individual, circumstantial and contextual aspects. To be able to use and re-use them to provide a desired outcome, creates 'positive' life experiences which, during Caregivinghood, kept the borders of the life spaces at bay.



The more SRRs a caregiver had access to in each GRR, the more options they had to resolve their challenges and the more 'positive' life experiences they were likely to be able to create (e.g. caregivers managed when facing challenges).

Theoretically, 'positive' life experiences, over time, strengthen the SOC and thereby they are involved in a positive health development. When describing an 'optimal' scenario during Caregivinghood, the positive themes uniting the essences of GRRs may thus unravel the 'mechanisms' that explain the association between a strong SOC and tension management. To be able to find a 'fit' thereby indicates having the ability to assess the situation correctly (comprehensibility). Having access to several GRRs, preferably in all domains, indicate access to a range of different SRRs, which enhance the options when facing challenges that needs to be resolved (manageability). The themes uniting GRRs thereby indicate that caregivers, or dyads, find it meaningful to try (meaningfulness).

Unfortunately, according to caregiving research and homecare experience, such an 'optimal' scenario rarely exists when the carerecipient has long-term care needs. The experience is considered dual, positive and negative, depending on when and what the viewer is focusing upon. At an individual level, the duality was context-related and dependent on what caregivers were referring to as none of the caregivers perceived their situation as solely positive or solely negative (a few were close to this end).

Findings indicate that this duality may be due to the fluctuation SRDs induce on the caregiver's, carerecipient's and dyad's ability to use available SRRs. When identifying SRDs/GRDs, it became apparent that this interplay at the individual level between characteristics generating SRDs/GRDs, was more prominent and complex than when identifying SRRs/GRRs. No caregiver had access to *all* their SRRs/GRRs *always*. SRDs indicated that, during certain circumstance, their habitual way to resolve a challenge did not work; they were unable to obtain a 'fit' (i.e. manage). In figure 6, this complexity is schematically presented through the use of some of the SRDs (blue circles in section 1) encompassed in the CG- and CR-domains (green circles in section 2) and SRRs as small squares; orange (usable), striped (fluctuating SRR), blue (unusable).

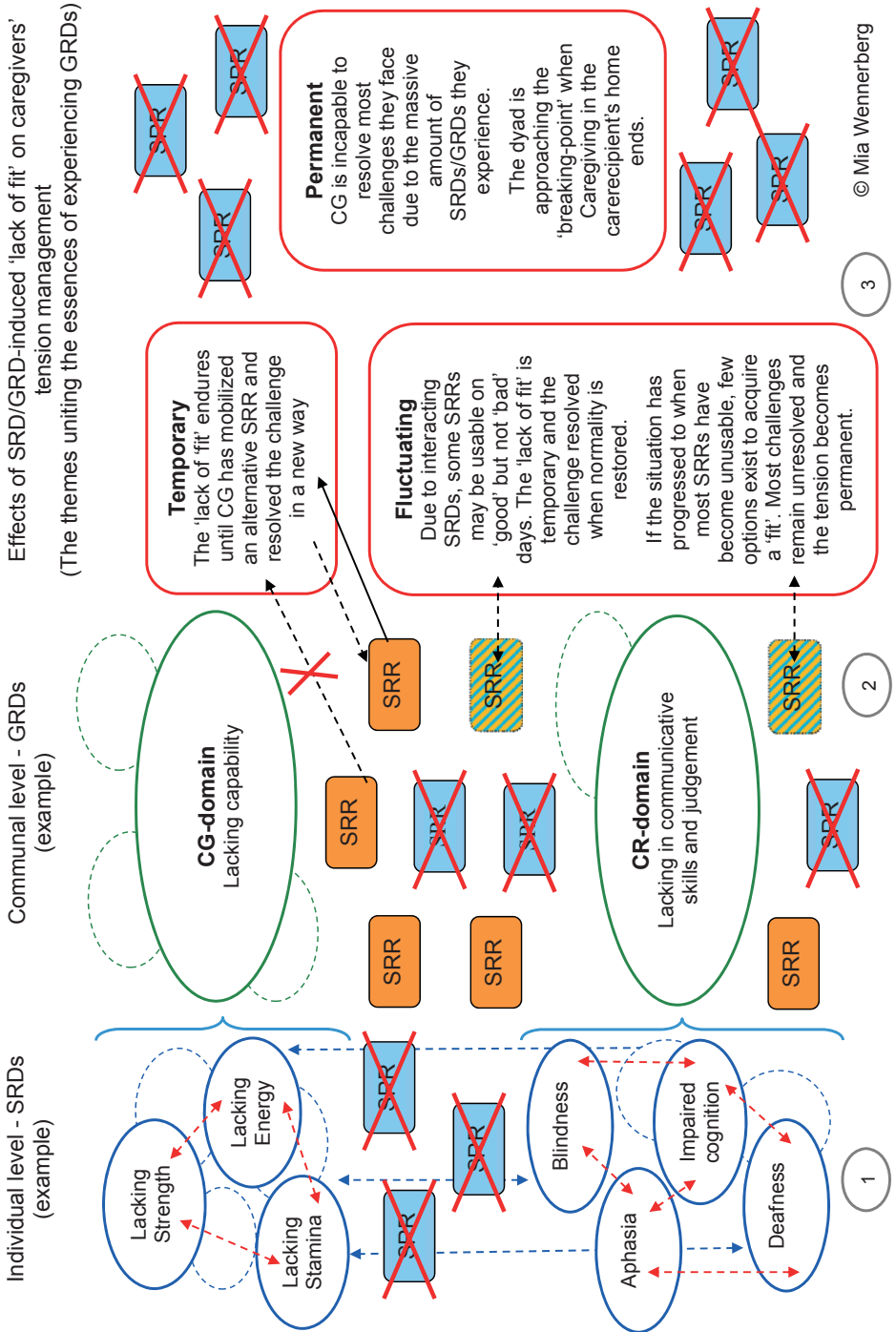
At an individual level, SRDs inducing 'lack of fit' were frequently due to concurrent SRDs in a domain (red arrows in section 1) or concurrent SRDs in different domains, (blue arrows in section 1), which the caregiver could not always discriminate between and make sense of (comprehensibility). The effects SRDs induced on the usability of SRRs during tension management could be temporary, fluctuating or permanent (red squares in section 3). Frequently SRDs decreased the usability of SRRs/GRRs in different domains simultaneously in a chain-reaction, or circular, manner, which affected a caregiver's motivation to try to resolve the challenge (meaningfulness). The 'lack of fit' was temporary if an alternative, usable SRR was found (i.e. the challenge became comprehensible, the appropriate SRRs were found and it seemed meaningful to try to resolve it). The 'lack of fit' was fluctuating, if a SRR was usable during certain individualized circumstances, not during others. Fluctuating SRRs (or vice versa regarding SRDs) added to the unpredictability of the situation (D-GRD) which negatively affected planning for the use of several SRRs, thereby caregivers' manageability.

When viewed out of a caregiver's perspective at an individual level, the borders of the life spaces (the domains) also seemed to be fluctuating, depending on their, or their dyad's, capability to find a 'fit'. Access to usable SRRs/GRRs kept the borders of the life spaces at bay and the dyad could continue through Caregivinghood as usual when a challenge had been resolved.

Each journey through Caregivinghood is unique, but the scenario is that the capability to find a 'fit' decreases and the life spaces shrink over time, at least in a group of caregivers such as the one participating in this study. Due to progress of diseases and an accumulation of deficiencies (SRDs), their carerecipients become increasingly dependent and less capable to cooperate and their caregivers progressively have to shoulder an ever-increasing workload. Towards the end of Caregivinghood (Figure 5), the caregiver and dyad is left with few, or no, usable SRRs/GRRs when facing challenges since most SRDs/GRDs have become permanent (red square section 3).

The situation has become (III);

- *Un-comprehensible*; stimuli from caregivers' internal and external contexts are unstructured, un-predictable and in-explicable
- *Un-manageable*; caregivers' inner trust in their capability to resolve challenges have disintegrated along with that regarding their carerecipient's and significant others' ability to assist
- *Meaningless*; since the presence of a multitude of SRDs/GRDs have drained all motivation for even trying to find usable SRRs when facing challenges.



**Figure 6.** Tension management when experiencing 'lack of fit'.

## DISCUSSION AND IMPLICATIONS

The overall aim of the study in this thesis was to derive congruent knowledge concerning what informal caregivers' Specific and Generalized Resistance Resources, SRRs/GRRs and Deficits, SRDs/GRDs may consist of, and to suggest how such knowledge may be used to promote their health. Findings from the study will therefore be discussed based on their theoretical and practical significance.

### Theoretical significance

The study was theory-driven, mainly qualitative and guided by Antonovsky's GRR-definition, the function of GRRs during tension management and the association between the type of life experiences this created and the strength of the SOC (10,11). The approach was thereby salutogenic and data was collected through salutogenically guided interviews (166-169) The theoretical significance of findings from this study have to be validated through discussions and future research, but seems to add to the theoretical framework in three ways.

At an individualized level SRRs and SRDs were unravelled as individual, circumstantial and contextual characteristics. SRRs were described as empowering, enabling and facilitating when caregivers faced challenges they needed to resolve. SRDs were the same type of characteristics but counteracted the use of SRRs, or indicated a lack of the appropriate ones. At group level these SRRs and SRDs were united as GRRs and GRDs encompassed in the four domains of Caregivinghood based on their origin (Table 7). This qualitative analysis induced a phenomena not in concordance with Antonovsky's descriptions, but may be detected in recent literature regarding GRRs and SRRs (191). The effect of uniting GRRs and GRDs at group level was that they became generalized in two ways. At an individual level, they encompass a caregiver's entire amount of SRRs/SRDs. At a generalized level, they encompass SRRs/SRDs described by the group of caregivers. Future theoretical discussions will have to determine whether GRRs and GRDs derived from this study is an evolvement of the original GRR- and GRD-concepts, or SRRs/SRDs in a new 'suit' that make findings usable for health promotion amongst caregivers. Either way, this phenomenon indicates that health promoting initiatives have to be conducted on two levels; the individualized regarding SRRs/SRDs, and the generalized regarding GRRs/GRDs.

Another addition to the theoretical framework is that the lack of a definition of GRDs made the identification of SRDs/GRDs problematic during the analysis. They were more frequently due to concurrent aspects within a caregiver's situation than SRRs/GRRs and were therefore more difficult to unravel (Figure 6). The 'backward' use of the GRR-definition and the theoretical function of GRRs, indicated that a 'serviceable GRD-definition' had been derived through an unintentional, implicit, alteration of the GRR-definition (10 p. 103). This 'definition' was essential and such a definition would probably be needed if future studies would use qualitative designs to unravel what these theoretical concepts may consist of in different groups. This GRD-definition was presented in paper III (alterations from the GRR-definition in *Italics*), and has to be validated in future discussions and research. GRDs are;

...physical, biochemical, artifactual-material, cognitive, emotional, valuative-attitudinal, interpersonal-relational, macrosociocultural...characteristics, phenomenon, or relationship... of an individual primary group, subculture, society *that is ineffective or contradicting a person's ability to avoid or combat a wide variety of stressors, therefore the tension is transformed into stress.*

The last addition to the theoretical framework, may be the most important. The design made it possible to make a theory-driven contextually grounded generalized synthesis of findings, wherein a core-theme described how the caregivers seemed to experience their situation during Caregivinghood; *Being situated in the duality of Caregivinghood* (Figure 5). Caregivinghood is viewed as a continuum in this synthesis; it has a beginning and it has an end. The 'optimal' scenario described through the themes uniting GRRs, may then be viewed as the health ease end-point of the theoretical health ease/dis-ease continuum. The 'worst case' scenario, uniting the essences of experiencing GRDs may thus correspond to the dis-ease end-point.

How the journey through Caregivinghood evolves, seems to be reliant on the access to usable SRRs/GRRs and the presence of SRDs/GRDs. When viewed in this manner, it seems as if findings from this study have unravelled what the actual resources and deficits involved in the elusive theoretical 'mechanisms' determining the strength of a person's SOC, may consist of (10, 11). Using the metaphor of 'health in the river of life' (Figure 1), it may be suggested that these resources and deficits, through a caregiver's tension management, determine her/his capability to 'swim' in their river of life; Caregivinghood. To present a way to describe these resources and deficits, thereby seem to be a significant contribution to the salutogenic framework. Such descriptions are essential when the intention is to design health promoting initiatives 'the salutogenic way' for individuals as well as groups of people, such as caregivers in a Swedish municipality.

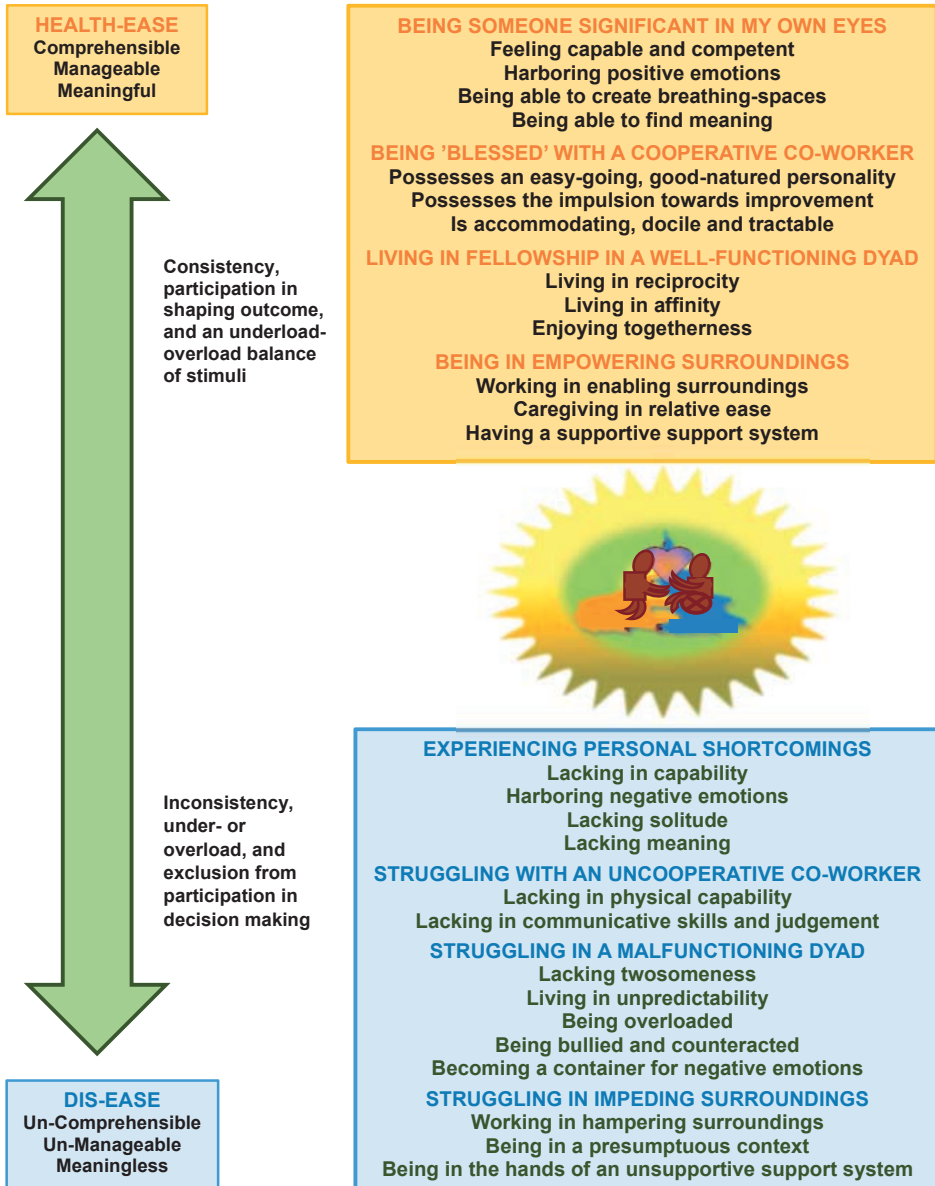
The theoretically grounded reasoning explaining why this type of health promotion ought to be effectuated is schematically shown in Figure 7. In this figure, the continuum of Caregivinghood has been merged with the salutogenic theoretical framework (10, 11) to visualize how the outcome of caregivers' tension management ('fit', 'lack of fit' in findings) is connected to movements along the health continuum.

### **Practical significance**

Findings from this study provide the opportunity to, theoretically, develop health promoting initiatives that focus on the plausible resources and deficits that through a person's tension management determine their SOC and thereby movements towards health (Figure 7). Such initiatives ought to make the journey through Caregivinghood a more positive, endurable, less unhealthy and devastating experience than caregiving research usually describe (24-26, 192)

Based on findings, this type of health promotion ought to focus on the preservation, if possible enhancement, of the specific (individual level) and generalized (group level) resources that enable caregivers to acquire a 'fit' during tension management.

Which GRRs move informal caregivers towards health?  
Which GRDs counteract such a movement?



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Figure 7. Caregivinghood within the salutogenic theoretical framework.

To preserve these salutogenic resources as available, also seems essential for the time when this phase of life ends, SRDs decrease and the caregiver regains access to SRRs, given they are still available. The goals for this type of salutogenic health promoting initiatives could be specified as;

- Preserve the usability of available SRRs/GRRs
- Eliminate or reduce SRDs/GRDs that make SRRs/GRRs unusable
- Provide GRRs when the appropriate SRRs/GRRs are lacking

Findings from the study (mainly the synthesis) provides certain ‘guidelines’ regarding important aspects when designing the suggested type of health promotion. Some practical examples connected to the unravelled resources and deficits are provided in this section, the papers include additional suggestions related to each domain (II-V). When discussing findings and plausible implications, it is essential to keep in mind that data was collected solely from the caregiver, who thereby serve as a proxy regarding resources and deficits in all domains.

A major finding was that the concept ‘caregiver support’ has to be defined/re-defined to be more in line with what caregivers need and want (193-196), at least when the intention is to promote caregiver health based on findings from this study. The change of perspective from a pathogenic to a salutogenic orientation, identifies much more resources and effects than what is usually taken into consideration when designing and providing the traditional type of ‘caregiver support’. The general guidelines that exist, at least in Sweden, are mainly designed out of a pathogenic perspective, thereby focused on the elimination of risks on a generalized level (193, 195, 196). This is the reasons to why the salutogenic concept ‘health promoting initiatives’ is used in these suggestions, unless referring to particular hands-on activities provided by formal care professionals (‘support’).

When designing health promoting initiatives, SRRs and SRDs represent the individualized level. Initiatives at this level should focus on *specific challenges*, or *groups of challenges* if a pattern (strategy) is discernable in the dyad’s particular caregiving situation. The character of SRRs and SRDs have the effect that they can only be described by the individual her-/himself or both in a dyad. To assess what is needed to increase a ‘fit’ or reduce a ‘lack of fit’, such an assessment may be conducted through the use of salutogenically guided conversations (166, 167, 182) complemented with appropriate assessment tools (e.g. 13, 162, 184) which will unravel resources as well as deficits (I). Such conversations ought to be conducted with the caregiver as well as with the carerecipient (42, 48, 103, 197), together or individually depending on the intention with the assessment. Salutogenic interviewing was used in the present study, and the evaluation indicated that this type of ‘data-collection’ could be a health promoting initiative in itself that may strengthen specific resources in the CG-, CR- and D-domains (I, II, IV).

An essential aspect during these assessments, is to have the ability to think in a new manner regarding individualized formal support (EC-SRR). Several caregivers seemed to need not yet developed types of support (EC-GRR) to be able to use their SRRs *within* the situation (III). New types of support, complementing the more traditional providing respite *from* the situation (198), could thereby promote the use of specific resources that enhance the experience of being a caregiver, or a dyad, *within* this situation (e.g. D-GRR *enjoying togetherness*).

At an individual level GRRs and GRDs indicate how ‘resourceful’ an individual, or dyad, is in different domains (II-V). The encompassed specific resources and deficits describe their options to acquire a ‘fit’ during different circumstances and the challenges inducing tension. On a generalized level, GRRs and GRDs encompass the group of caregivers’ resources and deficits (Figure 7). Health promoting initiatives provided on the generalized level should focus *on the domains of GRRs/GRDs*, to provide prerequisites needed to enhance the options to resolve challenges for the group of caregivers (V). To assess the type of initiatives the group of caregivers need to preserve the use of their specific resources, or to identify shared GRDs, the strategy suggested in paper I may be used. This strategy has four levels of ‘data collection’, whereof the first is individual. It is a strategy that involves caregivers, or dyads, as active participants in a manner that have been used by others (27, 199). This type of strategies exists on multiple levels (8, 162, 200-202).

When assessing needs to provide health promoting initiatives and formal support, findings from this study and research indicate that challenges during Caregivinghood are frequently resolved through *cooperation* (active or passive). To be able to cooperate and use the dyad’s amount of specific resources to acquire a ‘fit’, was especially essential for dyad functioning if both the caregiver and carerecipient had impairments (II, III, 103), particularly in situations where the EC-domain provided an essential amount of SRDs (V). In the study this was called ‘*dyad-specific tension management*’ (IV, 42, 48, 103, 197) and was described both by daughters and spouses. Depending on the intention with the assessment for health promoting initiatives, the caregiver-carerecipient has to be considered a *unit* (111, 174, 192, 203, 204), not merely separate individuals, even if the outcome may be initiatives directed towards specific domains of SRRs/SRDs (44, 45). If the dyad-specific tension management is not considered, the result may well be that the initiative is not accepted or used (103 and paper V).

On a generalized level, the dyad-specific tension management may be enhanced for all caregivers through health promoting initiatives encompassing dyads using the same type of specific resources or experiencing the same type of deficits (108, 109). One essential GRD to focus on such initiatives ought to be ‘Lacking in communicative skills and judgement’ originating from the CR-domain, but inducing specific deficits in all the other domains (III, IV, V). An additional aspect is to include the development of IT-skills amongst caregivers in caregiver education due to the increasing number of older adults who have access to the Internet. The caregivers’ organizations provide a wide range of accessible knowledge, skill-building programs and ‘help and advice’ pages (205, 206). Lack of knowledge, information and the time it took to find what they were searching for, was described as specific deficits by the caregivers participating in this study.



The synthesis describing the journey through Caregivinghood indicate that it seems essential to provide health promoting initiatives to maintain SRRs as available, even if they had become unusable during Caregivinghood. On group level caregivers rated their physical and psychological health as better than others their age, even if their psychological health had decreased since becoming a caregiver (Table 2). Qualitative data revealed that they were motivated to use specific resources to maintain their health (e.g. Nordic Walking, eat healthy food etc.), which indicate that they may have had access to specific resources that enabled them to preserve a '*preventive health orientation*' (10 p. 184). Primarily their motivation was described as stemming from a need to preserve health to manage caregiving. Even so, concurrent data indicated that some caregivers may be motivated by the insight that they would not provide care much longer (most daughters, healthy caregivers to care recipients whose health was deteriorating fast). These caregivers tried to maintain specific resources, such as their capability to drive a car or keeping social networks available, even if they seldom could use them. A few caregivers who had multiple health problems (CG-SRDs), experienced a range of deficits in most domains, did not seem to be motivated, or could not preserve their health resources. On a generalized level, the necessity to preserve health resources as available needs to be incorporated in information to caregivers, educational programs, and initiatives during the early stages of Caregivinghood (207).

Resources and deficits in the environmental/contextual domain (V) are essential determinants for the ability to acquire a 'fit' or experiencing a 'lack of fit' dependent on resources in other domains. A manner in which to provide enabling surroundings within the home, could be to consider caregivers as informal homecare 'workers' and the place where they provide care as their 'workplace' (V). In this manner, such SRRs as assistive devices, which in Sweden are being supplied in accordance with work regulations for formal care workers, would also be provided to all caregivers who wanted and needed them. Lack of appropriate beds, lifts et cetera were essential specific deficits for the caregivers and dyads in this study, as well as inappropriate cars and lack of parking permits.

At the individualized and generalized level, policies and regulations originating from most political arenas may induce resources as well as deficits; public transportation, outdoor accessibility and configuration, type and amounts of accessible apartments (housing policy), the location of shops, health care et cetera (V). The effect of these policies is usually due to a range of individual and circumstantial aspects, but also to regulations regarding such as queuing systems for adult day care, special transportation service and the ability to influence how and when formal support is provided (V). At the individualized level, the change of legislation in Sweden 2009 (208) made it obligatory for the municipalities to support their caregivers. Even so, an audit revealed that this change did not generate the *individualized*, flexible support of good quality that caregivers needed and wanted due to their individual circumstances (195, 196). To be generalized resources, policies affecting populations (i.e. caregivers), should be intersectoral and follow the intentions of the Ottawa Charter (175), 'Health in ALL Policies, HiAP' (209-211), the salutogenic model of wellbeing (212), the salutogenic definitions of quality of life (14) and health (13).

## METHODOLOGICAL CONSIDERATIONS

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No comparable study was found to guide the design, which thereby relied heavily on the research group's knowledge of salutogenic theory, caregiving provided in homecare settings and aspects associated with older adults' health, including policies et cetera. The description of the study in paper I is correct, but was considerably impaired by the knowledge as a PhD-student at that time. However, as additional knowledge was sought and acquired to be able to be more specific regarding methodology (177, 178, 189) and concepts when preparing the papers, the terminology became more appropriate. This aspect may affect trustworthiness in the reader's eyes, but should not reduce the trustworthiness of the study per se, since the data analysis had been completed almost three years before the need to publish paper I arose. This need was induced to acquire enough space to present GRRs and GRDs from each domain in separate papers. Even so, to have paper I published, became increasingly challenging the more papers we prepared and submitted. Paper I was blinded when a new paper was submitted and the methodology had to be described in a different manner in each subsequent paper (II-V). This aspect may add to the trustworthiness regarding the design, since additional descriptions associated with the methodology may be found in paper II-V. Retrospectively, it would have been easier, and faster, to present the study as a monography, instead of each domain in papers and the synthesis in this thesis.

The trustworthiness of findings may be questioned since they were derived through an analysis completed eight years ago. GRRs were initially described 30 years ago and these descriptions are still used in research (213, 214), even if few studies have evolved upon what they may consist of amongst caregivers and older adults (87, 142), and almost none describe GRDs (215). The generalized character of GRRs may thereby indicate that they do not change particularly much over time. However, more explicit descriptions ought to increase their usability when conducting health promotion in particular populations. During the last ten years, the theoretical development has been extensive (12). The investigator (author) has been able to follow some of this development, and the previously described theoretical significance of the study, may increase the internal and external trustworthiness regarding what GRRs and GRDs (190) may consist of, despite their 'age'. Even so, this significance has to be determined in further theoretical discussions and research.

At the individualized level, descriptions of what SRRs and SRDs may consist of were not found in previous research. A limitation of the study is that the caregiver served as a proxy for the carerecipient and dyad. This aspect has to be taken into account when evaluating findings and carerecipients ought to be offered participation in the data collection in future studies. The SRRs and SRDs in findings are subjected to contextual changes (see practical significance), and thereby 'time-reliant' in another manner than GRRs, and plausibly GRDs. Part time work during the time it took to prepare and publish the papers, enabled the investigator (author) to share findings with colleagues as a homecare nurse. This opportunity resulted in the testing of some of the implications suggested in paper I. One such example was increased documentation of resources in individual care-plans (162, 202) which could be used to work

more ‘salutogenically’ with the older people and caregivers homecare professionals met. Through timely education regarding salutogenesis to all professionals in the municipality, ideas regarding how to implement salutogenesis into the eldercare organization, arose. Findings from the study enabled the possibility to assist during such attempts. In one unit for dementia affected individuals, ‘salutogenic’ guidelines for the daily work were developed, applied practically, evaluated and rendered this unit a quality of care award. It was also possible to assist during the development of a ‘salutogenic’ strategy for the entire nursing home which increased activity, participation and interaction between individuals living in different units (8, 201), but also between the nursing home and individuals living in the surrounding village. This included a large neighboring unit for newly arrived refugees (2015), who were provided with the possibility to participate in activities, ‘work’ and interact with elderly individuals and staff within the nursing home. The aspect that findings could be implemented in these practical manners, may be considered a strength of the study if this type of implementations are evaluated through future research.

The trustworthiness of findings may be enhanced through the detailed description in paper I regarding the considerations that were made when the study was designed. These explanations describe the reasons to the choices regarding; the location, manner of recruitment of participants, method of data collection, why qualitative and quantitative data was collected, how data was structured to enable the particular type of analysis and how findings were derived. Due to the lack of previous studies using the same type of data collection and aim, a specific section was added in the interview-package to evaluate the interview technique (166-169, 182) and to acquire suggestions regarding methodological improvements in future studies. Data from this section was analyzed separately and has been presented out of the caregivers’, as well as out of the investigator’s (author’s) perspective (I).

Two methodological challenges for future research were suggested in paper I. Data was analyzed manually in the study, and the use of analytical software programs should be tested to reduce the time and costs for future research using the same type of design. Due to the collection of qualitative data during ratings of CADI-CASI-CAMI (184) and SOC-29 (11), the question regarding whether sums from these ratings were valid or not, arose (I). As trigger questions these questionnaires produced valuable data, but also revealed that the ratings were not reliable. This was the reason as to why quantitative data was only used to derive memos and descriptively in tables and figures. These discrepancies between qualitative and quantitative data, could be valuable to investigate further by the research groups specifically knowledgeable in the development and use of these instruments. The DSQ-questionnaire have been presented (supplement in II) and was essential during the analysis. It may plausible be used in other groups to unravel SRRs/GRRs and SRDs/GRDs, preferably with assistance from software programs, and after theoretical discussions associated with findings from this study have been conducted.

It may seem as a study limitation for readers not familiar with the homecare organization in Swedish municipalities (5, 193, 195, 196), that all traceable caregivers who were ‘known’ to professionals within one chosen municipality were offered partici-

pation and only a few were recruited through other sources (Figure 2). Through this manner of recruitment and the type of analysis, findings do not discriminate between sub-groups of participant descriptions, which was neither the intention.

In most studies, such discriminations are crucial to be able to assess the trustworthiness of findings, but to be useful in most Swedish municipalities, findings regarding GRRs and GRDs have to be representative for a municipality's *group* of caregivers. The reason is that the size of the group of caregivers to older adults, is usually too small to allow the development of generalized types of health promoting initiatives for specific sub-groups (179, 194). The caregivers participating in this study seem, based on homecare experience from different municipalities and knowledge regarding the particular municipality, heterogeneous enough (as do the described group of carerecipients) to be representative for municipalities similar to the one in this study. In this regard, the strategy to recruit caregivers and the type of analysis may be considered a strength that enhance the possibility to evaluate findings by implementing them in the previously described health promoting manner, on a generalized level in a Swedish municipality.

Ethical dilemmas during the interviews, as well as during the analysis, are described together with how these were managed in paper I. Reflexive processes and co-researchers holding metapositions were used to reduce biases due to preconceptions (177, 178, 189, 190). A specific ethical dilemma was encountered when citations were added in the papers to enhance the trustworthiness of GRRs/GRDs and to describe the variations within them. This dilemma was due to the requirement to add an interview-number. To reduce the risk that someone may identify particular caregivers through comparisons of citations with the same number across papers, these numbers were scrambled when citations were presented (e.g. caregiver one is not the same caregiver in any of the papers). Another aspect was that data describing the municipality was slightly altered to preserve the integrity of that specific eldercare organization (not investigator's). One aspect that may have affected the trustworthiness if quantitative data had been used in another manner, was the change of order when using the original CADI-CASI-CAMI-questionnaire (184). Out of ethical concerns and due to the salutogenic approach, the order between CADI and CASI was reversed, which derived a focus on satisfaction (CASI) before difficulties (CADI). The procedures used based on ethical considerations ought not affect the trustworthiness of findings. Instead, they may be considered a strength out of an ethical perspective, since they were in concordance with the information provided to the participants (181).

Through the additions paper II-V make to the description provided in paper I, methodological aspects seem to be transparent enough to be thoroughly scrutinized, thereby the trustworthiness of findings may be evaluated. The transferability (190) of findings may only be determined through theoretical discussions and further research, but it may be assumed, due to the generalized nature of GRRs and GRDs, that they could be transferrable in the manners presented in the discussion of findings in this thesis. SRRs and SRDs, however, are never transferable since they are individualized and context specific.

## CONCLUSION

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The theory-driven qualitative design added new knowledge regarding the salutogenic concepts SRRs/GRRs and SRDs/GRDs and a tentative GRD-definition. Findings indicate that GRRs, may have two levels; an individualized and a generalized, which make them more usable in health promoting initiatives than what was previously assumed. The study design also made it possible to derive a generalized synthesis of findings describing caregivers' experiences during this phase of life; *Being situated in the duality of Caregivinghood*. In this synthesis, Caregivinghood is viewed as a continuum similar to the theoretical health ease/dis-ease continuum. The themes uniting essences of GRRs and GRDs constitute the end-points of this continuum. Access to usable SRRs enables a caregiver to acquire a 'fit' and a desired outcome during tension management, thereby movement towards the health end are induced. The presence of SRDs, induce a 'lack of fit', thereby movements towards the dis-ease end. The ability to describe what SRRs and SRDs actually consist of, seem to unravel the elusive theoretical 'mechanisms' that determine the strength of the SOC, thereby a person's health development. This duality of caregiving has been described in caregiving research and findings could explain why it is dual, why Caregivinghood ends, and how this journey could be influenced to be a more positive and less unhealthy experience.

When the intention is to design salutogenic health promoting initiatives for caregivers based on findings from this study, the main goals ought to be; to preserve the usability of available SRRs/GRRs, eliminate or reduce SRDs/GRDs that make them unusable and provide GRRs when the appropriate SRRs/GRRs are lacking. Due to the nature of these resources and deficits, such initiatives should be conducted on two levels; the individualized (SRRs/SRDs) and the generalized GRRs/GRDs). The primary concern ought to be to re-define 'caregiver support' to encompass a wide variety of health promoting initiatives. A salutogenic approach requires a focus on resources in a wide sense to be able to develop new types of 'support' that do not exist today. On an individualized level this type of support seems likely to be SRR-preservers and SRD-eliminators *within* a situation, not merely the type that provides respite *from* it. To assist this way of thinking, the caregiver should be considered a 'worker' in a 'workplace' providing informal care. Aspects such as adequate education, equipment, the workplace's disposition and location, are thereby equally important for the informal care 'worker' as it is for the formal. It is also essential to consider the caregiver-carerecipient as a unit dependent on their ability to use their specific type of dyadic tension management to resolve challenges through cooperation. Assessments of 'support-needs' to bridge the gap between available, but not usable SRRs, should thus be conducted at the 'workplace' with both parties present. The journey through Caregivinghood is a shared journey, and the perspective of both travelers is equally important as is the preservation of their separate, but also shared, SRRs (and vice versa regarding SRDs).

On a generalized level, context matters since the use of individualized SRRs, or experience of SRDs, is associated with the prerequisites (GRRs/GRDs) provided by the environment and context. Local, National and International policy documents associated with health, human rights and equity, thereby has to be incorporated in

this intersectoral and multifaceted type of health promoting strategy. Inspired by the caregivers' comparison between Parenthood and Caregivinghood, the United Nations Principles of Older Persons should be added to this list of policy documents, especially when caregivers and carerecipients like the ones in this study are involved. If health promoting initiatives are designed in the suggested manner, it seems likely that not only caregivers would benefit, but most inhabitants in the context wherein this type of health promotion is conducted. However, findings regarding the salutogenic resources (SRRs/GRRs) and deficits (SRDs/GRDs) presented in this thesis, add new knowledge to the theoretical framework. The content in these concepts have rarely been described, subsequently further theoretical discussions and research has to be conducted to evaluate this knowledge.

## POPULÄRVETENSKAPLIG SAMMANFATTNING PÅ SVENSKA

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Som kommunköterska möter du ständigt äldre människor som bejakar livet och visar stor livsglädje. Denna livsglädje har varit mitt fokus under studier i omvårdnad och folkhälsovetenskap samt då jag använde min magisteruppsats om äldres livsglädje i en hälsofrämjande seniorutbildning i samarbete med Pensionärsuniversitetet. Under forskarutbildningen utgjorde denna kunskap om äldres livsglädje basen för den studie med fokus på anhängigvårdarens resurser till hälsa, som avhandlingen bygger på.

Demografiska faktorer och en utveckling där allt fler äldre (65+ år), med alltmer omfattande vård- och omsorgsbehov vårdas i sina hem av anhöriga eller nära vänner, här kallade anhängigvårdare,<sup>4</sup> innebär att de flesta välfärdssystem är beroende av att de är villiga och kapabla att ge denna vård och omsorg. Hur deras hälsa ska kunna bibehållas och främjas, utgör således en stor utmaning, för personal i äldreomsorgen som möter dem, för politiker som fattar beslut som berör dem och för forskare inom olika forskningsfält. Hur det ska gå till att möta denna utmaning, är dock omtvistat.

Traditionell anhängigvårdarforskning har oftast haft fokus på negativa effekter av att vårda en närstående och hur dessa effekter skulle kunna minimeras. Detta har givit viktig kunskap som förbättrat situationen för många anhängigvårdare. Detta patogena fokus har dock sedan 1990-talet alltmer ifrågasatts, då det anses ge en skev bild av anhängigvårdarens situation. Forskning visar att situationen, även för dem som vårdar närstående med stadigvarande och omfattande vårdbehov, består av både positiva och negativa aspekter. Tyvärr är kunskapen begränsad om de positiva aspekterna, enligt vissa forskare sannolikt till följd av att de negativa aspekterna ofta ligger till grund för olika typer av stödinsatser och policys. Denna brist på kunskap om de resurser anhängigvårdare använder för att må så bra som möjligt *trots* den situation de befinner sig i, har implikationer ur ett hälsofrämjande perspektiv. Hälsofrämjande insatser som syftar till att stärka resurser till hälsa, (i denna avhandling kallade 'salutogenic health promoting initiatives'), har varit mer framgångsrika i en rad olika kontexter, än de som fokuserat på negativa aspekter och risker. Denna salutogena form av hälsofrämjande insatser har sin teoretiska grund i Antonovsky's hälsoteori.

### Teoretisk referensram

Den salutogena hälsoteorin grundades av Aaron Antonovsky 1979 och han vidareutvecklade den 1987. Teorin är resursorienterad och fokuserar på hälsans ursprung, inte på orsaken till sjukdom. 'Hälsa' i teorin ses som ett kontinuum som sträcker sig från hälsa till ohälsa och utgångspunkter är att en person alltid befinner sig någonstans

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<sup>4</sup>Det finns en begreppsförvirring avseende benämningen på huvudpersonerna i denna avhandling. I denna svenska sammanfattning används en variant av Nationellt kompetenscentrum anhörigas (Nka) definition); 'I Nationellt kompetenscentrum anhörigas texter används ordet *anhörig* i bemärkelsen *person som vårdar eller stödjer en närstående*. Vanligtvis är den person som ger vård och stöd en *anhörig till den som tar emot stöd, omsorg eller vård*. *Närstående är den person som är i behov av stöd*' (<http://www.anhoriga.se/stod-och-kunskap/fakta-om-anhorig/vem-ar-anhorig/>). I denna svenska sammanfattning används huvudsakligen 'anhörigvårdare', vilket var den benämning som användes vid tiden då studien genomfördes.

utefter detta kontinuum. Antonovsky var intresserad av den 'mekanism' som får en person att förflytta sig närmre hälsa på detta kontinuum och kom fram till att de som befann sig närmre hälsopoolen hade en stark *Känsla av Sammanhang* (KASAM, eng. Sense of Coherence, SOC<sup>5</sup>). SOC definierades som ett globalt förhållningssätt, en livsorientering, som uttrycker i vilken utsträckning en person finner tillvaron *begriplig, hanterbar och meningsfull*.

I livets vardag utsätts alla människor för utmaningar som skapar spänningstillstånd som måste hanteras. För att hantera dessa utmaningar har en person tillgång till Specifika och Generella Motståndsresurser, (eng. SRRs/GRRs). Dessa resurser utgörs av individuella, kollektiva, materiella och immateriella karaktäristika (tex. Jag-styrka, kulturell stabilitet, pengar, socialt stöd). De specifika motståndsresurserna är individuella och användbara i vissa situationer och under vissa omständigheter. De generella är användbara för att hantera en rad olika utmaningar som skapar stress och de avgör vilka specifika motståndsresurser en person har tillgång till när de ska hantera dessa utmaningar ('tension management'). Om en person vid denna stresshantering har tillgång till specifika motståndsresurser som gör utmaningen begriplig och hanterbar, uppfattas det också som meningsfullt att spendera energi på att försöka uppnå den lösning som önskas. Lyckas personen med detta, skapas en positiv livserfarenheter ('life experience'). Uppreningar av denna typ av livserfarenheter över tid förstärker en persons SOC, och genererar därmed rörelsen mot hälsa. *Specifika och Generella Motståndsbrister* (SRDs/ GRDs) består av samma typ av karaktäristika som resurserna. När en person ställs inför utmaningar som skapar stress som måste hanteras, gör dessa brister att utmaningarna kan bli obegripliga, ohanterliga och att det därmed förefaller meningslöst att försöka lösa dem. Detta skapar över tid, negativa livserfarenheter som försvagar en persons SOC, vilket därmed skapar en rörelse mot ohälsa på hälsokontinuumet.

Ovanstående är ett förenklat sätt att beskriva en mycket komplex mekanism i en komplicerad teori. Antonovsky hade fokus på SOC och de generella motståndsresursernas funktion i teorin. Forskningen inom detta fält, har sedan teorin myntades huvudsakligen fokuserat på att mäta SOC och relatera dessa värden till olika aspekter som kan betraktas som generella motståndsresurser utifrån Antonovskys övergripande beskrivning. Denna forskning visar klart och tydligt att en stark SOC har stor betydelse för en positiv hälsoutveckling och att stärka en persons SOC anses därmed kunna stärka deras hälsa. Det problematiska är att väldigt lite kunskap finns om vad de resurser och hinder som påverkar styrkan i SOC består av, exempelvis för anhörigvårdare. I synnerhet gäller detta de specifika motståndsresurserna och de specifika och generella motståndsbristerna. Detta är en kunskapslucka som gör det svårt att arbeta resursfrämjande med enskilda anhörigvårdare, samt att utveckla salutogena typer av hälsofrämjande insatser för olika grupper, exempelvis anhörigvårdare i en kommun. Det är denna typ av kunskap studien designades för att generera.

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<sup>5</sup>I denna svenska sammanfattning kommer den engelska förkortningen 'SOC' att användas och, där det är nödvändigt, de engelska förkortningarna för specifika och generella motståndsresurser (SRRs/GRRs) och motståndsbrister (SRDs/GRDs). De engelska benämningarna på andra betydelsefulla begrepp i avhandlingen står inom parentes efter de svenska för att underlätta läsningen av avhandlingen och delarbetena.



## Syfte

Avhandlingens övergripande syfte var att generera kunskap om vad anhörigvårdares specifika och generella motståndsresurser (SRRs/GRRs) och motståndsbrister (SRDs/GRDs) består av samt att föreslå hur denna kunskap skulle kunna användas för att främja en positiv hälsoutveckling bland anhörigvårdare.

## Metod

Studiens teoretiska och metodologiska aspekter finns publicerade<sup>6</sup>. Designen var teoridriven och i huvudsak kvalitativ, med data insamlad genom enskilda intervjuer. Trettio två anhörigvårdare till närstående 65 år och äldre bosatta i en medelstor, västsvensk kommun, deltog i studien. Alla deltagare, utom tre, rekryterade genom kommunens biståndsbedömare ur det system för anhörigbidrag som den aktuella kommunen tillhandahöll<sup>7</sup>.

Anhörigvårdargruppen utgjordes av 17 kvinnor, nio män och sex döttrar, medelåldern var 71 år (50-87 år)<sup>8</sup>. Gruppen närstående utgjordes av nio fruar, sex mödrar och 17 makar, medelåldern var 77 år (63-97 år)<sup>9</sup>. I gruppen närstående fanns en rad olika skäl till varför de behövde stöd och hjälp, från generell ålderssvaghet till mycket omfattande vårdbehov. Vårdbehovet varierade därmed kraftigt, från en av de äldsta mödrarna som klarade sig själv med hjälp från dottern ett par gånger i veckan, till partners som aldrig kunde vara utan tillsyn. Sexton anhörigvårdare hade stöd i arbetet från hemtjänstpersonal och andra källor<sup>10</sup>. Tjugonio närstående var av biståndsbedömare bedömda att ha stadigvarande vårdbehov i en omfattning som uppfyllde kriterierna för anhörigbidrag. De tre par som av olika skäl inte hade ansökt, skilde sig inte från de övriga i gruppen i något annat avseende än att deras närstående inte erhöll anhörigbidraget.

Data samlades in genom salutogent guidade intervjuer<sup>11</sup> och fokus låg på hur och varför anhörigvårdarna löste de utmaningar de ställdes inför på sitt specifika sätt (SRRs) och varför detta ibland inte var möjligt (SRDs). Alla intervjuer bandades i sin helhet. Data analyserades först på individnivå, vilket gav individualiserade motståndsresurser och motståndsbrister (SRRs/SRDs), och därefter på grupp nivå, vilket gav de generella motståndsresurserna (GRRs/GRDs) som förenade alla deltagarnas motståndsresurser och motståndsbrister på grupp nivå. När data var analyserad kunde en syntes av dessa resultat göras baserat på teorin och de motståndsresurser och motståndsbrister anhörigvårdarna beskrivit<sup>12</sup>. Denna syntes kallades Anhörigvårdarskapet ('Caregivinghood') och kan ses som en fas i livet, precis som föräldraskapet som flera anhörigvårdare jämförde med när de beskrev olika utmaningar de var tvungna att hantera.

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<sup>6</sup>Delarbete I

<sup>7</sup>Figure 2. The recruitment process (modified version from paper II)

<sup>8</sup>Table 2. Caregiver characteristics (modified version from paper II and V)

<sup>9</sup>Table 3. Carerecipient characteristics (modified version from paper II and V)

<sup>10</sup>Table 4. Caregivers' formal and informal support (modified version from paper V)

<sup>11</sup>Table 6. The phases of the interview (modified version from paper III)

<sup>12</sup>Figur 3. Memo use during the analysis. Figure 4. The process of data analysis. Figure 5. Being situated in the duality of Caregivinghood

Baserat på ursprunget till motståndsresurserna och motståndsbristerna, kunde dessa härledas till fyra olika domäner<sup>13</sup>; anhängvårdaren själv ('caregiver, CG-domain'), den närstående ('careerecipient, CG-domain'), anhängvårdarens och den närståendes delade domän ('dyadic, D-domain') och den omgivning anhängvårdandet skedde i ('environmental/contextual, EC-domain'). I samtliga domäner finns grupper av specifika motståndsresurser och motståndsbrister som förenats i de generella. Två teman i varje domän beskriver upplevelsen av att ha tillgång till motståndsresurser samt att erfara motståndsbrister, under denna fas i livet; Anhängvårdarskapet<sup>14</sup>.

## Resultat

De fyra domänen med sina respektive motståndsresurser och motståndsbrister är presenterade i delarbeten i denna avhandling och i dessa finns citat från intervjuerna som visar specifika motståndsresurser/-brister. Anhängvårdarnas upplevelse av att befinna sig i anhängvårdarskapet, baserat på de motståndsresurser/-brister de beskrev, är presenterat i avhandlingens resultatdel ('Findings'). Det övergripande temat som beskriver denna upplevelse blir, för att fånga det anhängvårdarna beskrev, i svensk översättning; '*Att vara placerad i Anhängvårdarskapets berg och dalbana*' ('*Being situated in the duality of Caregivinghood*'). 'Att vara placerad i', syftar på aspekter som har att göra med att en del anhängvårdare inte ansåg sig ha något annat val än att bli anhängvårdare, både av moraliska och kvalitetsrelaterade skäl. 'Berg och dalbana' hänvisar till den dubbelhet som finns under denna fas i livet, det vill säga, både positiva och negativa aspekter. Dessa aspekter har att göra med fluktuationen som finns när det gäller hur användbara en anhängvårdarens specifika motståndsresurser (SRRs) är och hur frekvent deras specifika motståndsbrister (SRDs) gör dem oanvändbara. Under vissa omständigheter fungerar dessa resurser, under andra gör de det inte. Detta gör att anhängvårdarskapet synes vara präglad av en oberäknelighet där det enda man som anhängvårdare säkert vet är att ju längre tiden går, desto sämre blir den man vårdar, och desto svårare blir det att finna användbara specifika motståndsresurser när man ställs inför utmaningar som behöver lösas. De flesta anhängvårdare är väl medvetna om att så småningom går det inte längre att vårda i hemmiljön och anhängvårdarskapet, så som det beskrivs i denna avhandling, upphör. Anhängvårdaren och den närstående har då nått slutet på berg och dalbanan, till följd av att de har alltför få användbara specifika motståndsresurser i förhållande till alla de hinder för dess användning som de upplever när de ställs inför alltför och allt svårare utmaningar.

## Diskussion och slutsatser

Avhandlingens studie hade ett övergripande syfte som består av två delar;

- att generera kunskap om vad anhängvårdarens specifika och generella motståndsresurser och motståndsbrister består av (studiens teoretiska resultatdel).
- att föreslå hur denna kunskap skulle kunna användas för att främja en positiv hälsoutveckling bland anhängvårdare (studiens praktiska resultatdel)

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<sup>13</sup>Delarbete II-IV

<sup>14</sup>Table 7. Domains themes GRRs and GRDs in Caregivinghood

## **Teoretisk betydelse**

Resultat från studien tillför kunskap som fyller en teoretisk kunskapslucka på flera olika sätt, förutsatt att dessa fynd utvärderas genom teoretiska diskussioner och framtida forskning. Det var möjligt att använda Antonovskys definition av generella motståndsresurser (GRR-definitionen) och de beskrivningar av de olika begreppens funktion som fanns för att, genom en kvalitativ analys, identifiera vad motståndsresurserna/-bristerna bestod av. De specifika motståndsresurserna (SRRs) var individuella, kontextuella och användbara under, för anhörgivårdaren, specifika omständigheter. Då gav de alltid det förväntade resultatet. Exempelvis att byta miljö för att kunna använda fler specifika resurser, vilket gav ökad livsglädje och gemenskap;

*'...vi är ute och går där ute i bergen...man kommer 200 m från campingen å då hör man inte trafiken utan de e alldeles TYST...gå ut å ta en promenad på stranden å att vi tar rullstolen med oss...å hälsar på nån ...överhuvudtaget FINNAS TILL...å att bena fungerar när jag kliver ur sängen på morronen...'* (CG 21)

Att identifiera motståndsbrister (SRDs/GRDs), var mer komplicerat. Dels på grund av att Antonovsky aldrig definierat de generella motståndsbristerna, annat än genom beskrivningar av de negativa effekterna de har på en persons möjlighet att hantera utmaningar som skapar stress, och därmed effekten på deras SOC. Under analysen berodde specifika motståndsbrister ofta på samverkande faktorer. Exempelvis; om parkeringen inte var skottad, anhörgivårdaren var trött och den närstående inte kunde hjälpa till vid förflyttningar, så gjorde dessa motståndsbrister sammantaget att det var omöjligt vid detta tillfälle att använda bilen för att besöka barnen. I detta exempel gjorde samverkande specifika motståndsbrister det omöjligt att använda den specifika motståndsresursen till ökad gemenskap; att besöka barnen. Efter analysen blev det uppenbart att en intuitiv GRD-definition hade skapats för att identifiera motståndsbrister och den har publicerats<sup>15</sup>. Denna typ av definition behöver utvärderas i framtida teoretiska diskussioner och forskning. En definition synes däremot nödvändig om kvalitativa data ska användas för att ta reda på vad motståndsbrister kan bestå av, eftersom deras samverkande karaktär erbjuder olika möjligheter att reducera deras negativa effekter.

En aspekt som avviker från teorin är att de generella motståndsresurserna/-bristerna (GRRs/GRDs), genom dataanalysen blev generella på två nivåer. På individnivå innehåller en generell motståndsresurs alla specifika motståndsresurser en anhörgivårdare har i en domän, exempelvis alla som kommer från henne/honom själv. De visar därmed hur 'resursstark' en anhörgivårdare är inom denna domän. Samtidigt innehåller denna generella motståndsresurs (GRR), samtliga anhörgivårdares beskrivna specifika motståndsresurser, det vill säga hur 'resursstarka' de är som grupp. Detta har betydelse för utformningen av hälsofrämjande insatser, då dessa behöver bedrivas på två nivåer, den individuella för enskilda anhörgivårdare och den generella avseende gruppen anhörgivårdare, exempelvis i en kommun.

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<sup>15</sup>Delarbete III

Det mest betydelsefulla resultatet var att det var möjligt att beskriva vad specifika motståndsresurser och motståndsbrister (SRRs/SRDs) kan bestå av. Anhörigvårdarskapet kan ses som ett kontinuum, precis som hälsokontinuumet i den salutogena teorin. I syntesen av resultaten förenar temana innebörden i att ha tillgång till generella motståndsresurser (GRRs), eller uppleva generella motståndbrister (GRDs) på gruppnivå<sup>16</sup>. Exempel på sådana teman (från anhörigvårdardomänen) är; *'Att vara betydelsefull i sina egna ögon'* (GRR-tema) och *'Att uppleva sig som otillräcklig'* (GRD-tema). Om dessa teman ses som ändpunkter på Anhörigvårdarskapets kontinuum, beskriver de specifika motståndsresurserna/-bristerna (SRRs/SRDs) vad det är på individnivå som ger upphov till rörelsen längs kontinuumet. Det vill säga, den 'mekanism' som, enligt den salutogena teorin, påverkar styrkan i en persons SOC<sup>17</sup>.

Forskningen är samstämmig avseende sambandet mellan styrkan i SOC och en persons hälsoutveckling. De flesta studier som visar denna typ av samband, föreslår att anhörigvårdarens SOC ska stärkas för att de ska klara av anhörigvårdarsituationen med minsta möjliga negativa påverkan på deras egen hälsa. Resultaten från den här studien visar att det går att ta reda på vad dessa motståndsresurser består av, därmed vad som ska stärkas och bibehållas, samt vad som utgör motståndsbrister som bör reduceras/elimineras. Detta har inte beskrivits tidigare och utgör ny teoretisk kunskap som är användbar i en salutogen utformat hälsofrämjande strategi, förutsatt att resultat från denna studie verifieras genom teoretiska diskussioner och fortsatt forskning.

### **Praktisk betydelse**

Studiens resultat visar på en rad olika aspekter som behöver beaktas om intentionen är att utveckla salutogena typer av hälsofrämjande insatser för anhörigvårdare. I huvudsak handlar detta om att utforma insatser som på en individuell nivå hjälper anhörigvårdarna att bibehålla och använda sina specifika motståndresurser (SRRs) samt att eliminera och reducera specifika motståndsbrister (SRDs). Exempel på sådana individualiserade insatser skulle kunna vara bostadsanpassning eller datautbildning för att kunna söka information och sköta bankärenden, beroende på vad som skapar utmaningar som enskilda anhörigvårdare behöver lösa.

Det primära i en sådan hälsofrämjande strategi är att skapa en ny definition av 'anhörigstöd'. En salutogen ansats innefattar så många fler möjligheter att främja hälsa, genom att bibehålla och möjliggöra resursanvändning, än den traditionella ansatsen som fokuserar på motståndsbrister. Båda typerna behövs och kompletterar varandra, men resultatet tyder på att nya, ännu ej beprövade, stödformer behöver utvecklas för att bibehålla motståndsresurser. Detta gäller framför allt på den individuella nivån, där anhörigvårdarna ofta beskrev sitt behov av stöd i situationen för att kunna använda sina motståndsresurser (SRRs), inte enbart stöd som innebar att de flyttades *ur* situationen, exempelvis växelvård.

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<sup>16</sup>Table 7. Domains themes GRRs and GRDs in Caregivinghood

<sup>17</sup>Figure 5. Being situated in the duality of Caregivinghood. Figure 6. Tension management when experiencing 'lack of fit'. Figure 7. The continuum of Caregivinghood within the salutogenic framework.

Under intervjuerna ställdes en konkret standardfråga avseende vilken typ av stöd anhängigvårdaren skulle vilja ha, som vid den tidpunkten inte fanns. För en kvinna skulle en sådan resursstödande insats ha varit en 'tvättservice' som hämtade tvätten vid dörren och lämnade den igen efter någon dag, eftersom tvätt bestyr var hennes absolut största specifika motståndsbrist. En annan kvinna hade flera konkreta förslag avseende generella motståndsresurser;

*'jag har funderat faktiskt på...att få prata med någon psykolog...dels tror jag kanske att [maken] skulle behöva det och dels tror jag att det skulle vara bra för mej också...därför att jag...jag har lite svårt att bedöma om jag ställer för höga krav...på honom...*

*...jourhavande anhängigvårdarstödjare... alltså...i princip som jourhavande medmänniska.... nån som man kan ringa till....prata av sig...ett bollplank....tankar å sånt här...å även då få lite....tips....se saker ur en annan vinkel....för att det blir ju gärna så att.....man kan köra fast helt enkelt...tänker för enkelspårigt....eller har inte ork.... å lyfta blicken lite högre alla gånger... '(CG 6)*

Flera anhängigvårdare hade erfarenhet av arbete som formella vårdare inom äldreomsorgen, varav tre hade över 25 års erfarenhet<sup>18</sup>. De hänvisade ofta till den erfarenheten som en specifik motståndsresurs de använde för att lösa olika utmaningar. Om anhängigvårdare ses som 'vårdpersonal' som ger vård och omsorg på en 'arbetsplats'<sup>19</sup>, skulle de genom olika avtal, direktiv eller policys, kunna ges samma förutsättningar som formell vårdpersonal har i en informell kontext. Detta torde innebära att anhängigvårdarna skulle kunna utföra sitt arbete med så liten negativ hälsopåverkan som möjligt. Detta synsätt skulle exempelvis innebära utbildning i lyftteknik, läkemedelshandling, olika typer av hjälpmedel på 'arbetsplatsen' et cetera. I detta sammanhang är det även väsentligt att all biståndsbedömning sker i hemmet, det vill säga, på den gemensamma 'arbetsplatsen' där två personer är involverade; dyaden anhängigvårdarenärstående. Många anhängigvårdare beskrev hur paret löste sina utmaningar genom samarbete och gav exempel på deras unika sätt att hantera sina gemensamma utmaningar (dyadic tension management<sup>20</sup>). Denna unika typ, baserade sig på deras gemensamma referensram av värden och erfarenheter och användes även av döttrarna, men på ett lite annorlunda sätt. Båda parter motståndsresurser och motståndsbrister är således lika viktiga att ta i beaktande när individuellt anpassade hälsofrämjande insatser erbjuds, eftersom de gör resan genom anhängigvårdarskapet tillsammans.

På en generell nivå handlar hälsofrämjande insatser om att skapa kontextuella förutsättningar (GRRs) för att gruppen anhängigvårdare att kunna använda sina individuella motståndsresurser (SRRs). Exempel på sådana generella motståndresurser (GRRs), baserat på studiens resultat, är att skapa tillgängliga miljöer, transportsystem, utbildningsinsatser, fler lägenheter med god tillgänglighet, förändra regelverk för färdtjänst och handikapp parkeringstillstånd et cetera<sup>19</sup>. I detta arbete bör olika lokala, Nationella och Internationella policydokument kopplade till hälsa, mänskliga rättigheter

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<sup>18</sup> Table 2. Caregiver characteristics (modified version from paper II)

<sup>19</sup> Delarbete V

<sup>20</sup> Delarbete IV

och tillgänglighet för alla, användas som styrdokument. När anhörigvårdare och närstående som de i denna studie är involverade borde, baserat på deras jämförelse med föräldraskapet, FN's principer för äldre personer läggas till dessa styrdokument. De projekt som utvecklar denna typ av salutogen utformade hälsofrämjande strategier, bland annat på kommunnivå utomlands, visar på vikten av att de är intersektoriella, involverar alla politikområden och bedrivs med aktivt deltagande från målgruppen själva<sup>21</sup>. Om denna typ av generella hälsofrämjande insatser utvecklas på det sätt som beskrivits i denna avhandling, exempelvis i en kommun, är det troligt;

- att resan genom Anhörigvårdarskapet för de anhöriga och deras närstående skulle kunna bli en mer positiv och mindre ohälsosam upplevelse än vad forskningen oftast beskriver
- att anhörigvårdarna skulle få ett gynnsammare utgångsläge med fler tillgängliga motståndsresurser när anhörigvårdarskapet upphör
- att kommunerna ges ett verktyg för att kunna uppfylla sina åtaganden och därmed en möjlighet att utveckla intentionerna om ett individualiserat, flexibelt och kvalitativt anhörigstöd<sup>22</sup>

Två ytterligare effekter om denna typ av resursfrämjande strategi utvecklades på det sätt som beskrivits, torde kunna bli att inte bara anhörigvårdares hälsa gynnas, utan sannolikt borde det ge gynnsamma effekter för hela befolkningens hälsa i den kontext den används. Sannolikt skulle denna strategi även ha positiva effekter för den organisation som har det praktiska och ekonomiska ansvaret för äldreomsorgen.

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<sup>21</sup>Delarbete V

<sup>22</sup>Riksrevisionens granskning, 2014, avseende utfallet av ändringen av 5 kap. 10 § socialtjänstlagen, 2009 (se referenslista)

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